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# Understanding Women's Concerns and Coping with Worry of Breast Cancer Recurrence

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A thesis submitted in partial fulfilment of the requirements for the Degree of  
Doctor of Clinical Psychology, The University of Auckland, 2012.

## Abstract

Worry of cancer recurrence is prevalent among survivors of breast cancer. It can persist for years and undermine women's psychological wellbeing and overall adjustment. Thus far, we have limited knowledge about the individual, treatment and psychosocial characteristics that account for variations in worry of recurrence and its influence on psychological adjustment post treatment. Such knowledge is needed to inform interventions directed at alleviating recurrence worry, and improving psychological functioning in breast cancer survivors.

Prior research suggests that more recent time since diagnosis, younger age, chemotherapy and trait anxiety contributes to psychological wellbeing. Whether these factors also contribute to worry of recurrence remains to be determined. Moreover, little is known about how women's beliefs about their cancer, influence worry of recurrence, or how women manage their worry of recurrence, and whether some coping strategies are more effective than others.

The current study aimed to address these research gaps by evaluating worry of recurrence, coping with cancer worry, psychological wellbeing and quality of life among breast cancer survivors. The Common Sense Model of Self-Regulation was used as the guiding theoretical framework. The project also included the design and pilot testing of a new measure, Coping with Worry of Cancer Recurrence.

A sample of 143 women who were in remission from breast cancer were recruited through the New Zealand Cancer registry. Participants completed two questionnaires, each a month apart; 97.9% completed both questionnaires. Analyses revealed that younger age, higher trait anxiety, and receiving chemotherapy and hormonal treatment were associated with greater worry of recurrence. In relation to cancer beliefs, perceptions of a more chronic

timeline, more severe consequences and experiencing more symptoms perceived as a recurrence, predicted higher levels of worry of recurrence. With regards to coping strategies, emotional expression and optimistic thinking predicted lower levels of concurrent worry, while optimistic thinking and spirituality predicted decreases in worry of recurrence over time. Conversely, avoidance and problem solving strategies were associated with greater concurrent worry of recurrence, with avoidance also predicting increases in worry over time. Overall, the findings elucidate various factors associated with worry of recurrence, including illness beliefs and coping strategies. These findings can inform the development of psychological treatment of distress, by highlighting targets for intervention. Moreover, they can inform medical professional's communications with women with breast cancer by identifying information that may be beneficial in circumventing distress.

## Acknowledgements

I wish to recognize those, without whom, completion of this thesis would not have been possible. First and foremost, I owe my deepest gratitude to all the women who participated in this study and shared their experiences with me.

To my husband Garth and my son Liam, who are, and have always been my most constant source of love, support and encouragement. Thank you for always being there for me.

To my supervisor, Professor Linda Cameron, I truly valued your guidance, knowledge and encouragement. I could never thank you enough for all of your support.

To the best grandparents a child could ever ask for (Mr and Mrs Bidda Veerasamy) – I only wish you could have seen me complete this! You will always inspire me to do better and I could never thank you enough for all the special memories and for how much the both of you adored me.

To my family – Dad (Pooban Naidoo), Mum (Jacie Naidoo), Gishern, Luvern and Remolan. Thank you for always believing in me. I feel blessed to have such a supportive and loving family.

To my friends, Virginia Farnsworth, Rachael Mayne, Sarah Bramhall and Nicola McCalliog - thank you for all the fun times, advice, motivation and your belief in me.

~ I dedicate this thesis to my husband and my son ~

Garth Rogers and Liam Rogers

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## List of Abbreviations

Abbreviation	Full expression	Initial page number
CSM	Common Sense Model	4
IPQ	Illness Perceptions Questionnaire	29
IPQ-R	Illness Perceptions Questionnaire	29
AIR-R	Assessment of Illness Representations Revised	29
IES-R	Impact of Events Scale Revised	36
HADS	Hospital and Depression Scale	57
NZCR	New Zealand Cancer Registry	80
SF-36	Short Form 36 Quality of Life Measure	86

## OVERVIEW

Breast cancer is the most common form of cancer inflicting New Zealand women with approximately 2500 cases being diagnosed each year (Ministry of Health, 2008). Estimates indicate that 1 in 9 women will be diagnosed with the disease during their lifetime (Ministry of Health, 2008, p. 216). It is also regarded as the leading cause of cancer-related deaths in New Zealand, responsible for approximately 600 women dying from the disease each year. However, despite the incidence of the disease increasing over the past 50 years, survival rates in women have actually improved over this time (Dawood et al., 2008). This has been attributed to increased awareness, earlier diagnosis due to mammography screening (Nyström et al., 2002) and improvements in medicine including increased use of systemic adjuvant therapies (Vervoort, Draisma, Fracheboud, van de Poll-Franse, & de Koning, 2004).

Nevertheless, while extended survival is generally positive overall, the prognosis for each individual is often unknown and unpredictable. Given the uncertainty most women face following treatment, it is not surprising that so many experience worry of cancer recurrence. Research indicates that 60.0 % to 90.0 % of breast cancer survivors suffer from worry that their cancer may return (Mast, 1998; Schover, Yetman, Tuason, Meisler, Esselstyn, & Hermann, 1995). Unfortunately for up to 70.0% of survivors, these worries endure for up to five years following diagnosis (Mast, 1998) and have been associated with psychological distress (Costanzo, Lutgendorf, & Mattes, 2007). For many women their worry of cancer recurrence stems from what this could mean for them including the possibility of death, enduring further treatment particularly chemotherapy, suffering psychological distress, experiencing pain, the advancement of cancer, the suffering of family members and losing their breast (Vickberg, 2001).

It has been found that despite worry of recurrence being a predominant concern, more than half of breast cancer survivors indicate that their worries have not been attended to even though they deem it a moderate to high need following cancer treatment (Stanton et al., 2005). Overall, the prevalence and prolonged nature of cancer worry in women has warranted a better understanding of recurrence worry so that better interventions may be designed and put in place to assist women in dealing with their worry. In essence, better management and treatment of recurrence worry are likely to have important consequences for women post breast cancer treatment, including improving their adjustment, overall wellbeing and quality of life.

## CHAPTER I: INTRODUCTION

There is no widely accepted definition of worry of recurrence (Cameron & Moss-Morris, 2010), however, Vickberg (2003) defines fear of recurrence as the worry or fear that the cancer will return or progress in the same organ or in another part of the body. While the term ‘fear of recurrence’ is commonly used in research, it may be conceptualised as a more extreme, less frequent experience whereas worry encapsulates variations in distress about the possibility of cancer recurrence. As such, the current study focuses on women’s worry of cancer recurrence.

Research thus far has examined the relationship between cancer worry and the demographic variable of age (Deimling, Bowman, Sterns, Wagner, & Kahana, 2006), psychological distress (Costanzo et al., 2007) and time since diagnosis. However, few studies have examined the relationship between adjuvant treatment, trait anxiety, quality of life, illness representations (ie. threat appraisals) of breast cancer and coping strategies on levels of worry of recurrence. As such, the current study aims to elucidate these relationships, and in addition examine the relationship between various domains of women’s quality of life and their worry of recurrence. Furthermore, this study will add to existing literature by examining associations between age, psychological distress and time since diagnosis in New Zealand breast cancer survivors.

This investigation includes a pilot study outlining the design and validation of a ‘Coping with Worry of Cancer Recurrence Measure’ which will be used to examine the relationship between coping and cancer worry in breast cancer survivors. It has been noted upon examination of the literature that research pertaining to women’s coping post breast cancer treatment has concentrated predominantly on general emotional coping as opposed to examining coping strategies specifically targeted at reducing recurrence worry.

It is likely that an understanding of how women's threat appraisals and coping influences their worry of cancer recurrence will help shape future psychological treatments and support services for breast cancer survivors. In addition, it is anticipated that the current study would help identify those cancer survivors who are more likely to experience higher levels of cancer worry and psychological distress post treatment, hopefully warranting early intervention.

The literature review will be presented in eight sections, with the first section providing a brief overview of the research to date regarding women's psychological wellbeing and quality of life following breast cancer. Section 2 and 3, will present research pertaining to the relationship between women's worry of cancer recurrence with age, and adjuvant cancer treatment respectively. Section 4 introduces studies investigating the associations between worry of recurrence and psychological adjustment. It will also present current research on the associations between worry of recurrence and time since diagnosis. Section 5 introduces literature pertaining to Leventhal's Common Sense Model (CSM) of Self-Regulation which is framework that will be used in the current study to understand women's breast cancer representations or threat appraisals. This section will include studies to date investigating how individual's illness perceptions impact their level of cancer worry. Section 6 will examine the literature relating to women's coping following treatment for breast cancer and its relationship to psychological adjustment including worry of recurrence. Finally section 7 provides a summary of the main aspects of the literature review and Section 8 provides an outline of the current study and its hypotheses.

### **Section 1. Quality of Life and Psychological Wellbeing in Breast Cancer Survivors**

Quality of life may be conceptualized as capturing the physical, psychological, social and spiritual domains of an individual's life (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998). Studies investigating the challenges of survivorship and impacts of being diagnosed

with breast cancer have highlighted the following issues impacting quality of life in breast cancer survivors: anxiety, depression, uncertainty about the future, body image issues, worries of recurrence, treatment related distress, role difficulties, financial difficulties, pain, disruptions in daily activities and interpersonal problems (Ferrell et al., 1998; Polinsky, 1994; Quigley, 1989; Schag et al., 1993).

The current literature review focuses on three areas: the physical wellbeing, social and role functioning difficulties and body image aspects of women's quality of life; the psychological wellbeing of breast cancer survivors post treatment; and the impact of trait anxiety on women's quality of life and psychological wellbeing. It is important to review research pertaining to women's quality of life issues following a breast cancer diagnosis, as it is likely that these difficulties impact women's worry of cancer recurrence. An overview of the psychological wellbeing of breast cancer survivors is also warranted given that worry of recurrence has been identified as a significant contributor to poorer psychological outcomes. Furthermore, as trait anxiety is a predictor of women's quality of life and psychological wellbeing, a review of related research is considered relevant due to its likely association with worry of recurrence in the current study.

***Physical wellbeing, social and role functioning and body image issues in breast cancer survivors.***

Following a diagnosis of breast cancer, women experience many difficulties, particularly relating to their physical wellbeing, social and role functioning and their body image. The current study investigates if a relationship exists between women's worry of recurrence and various domains of quality of life. An understanding of the challenges women experience may be relevant in interpreting the underlying reasons for any relationship uncovered between women's worry of recurrence and respective domains of quality of life. An investigation of this link is also likely to provide some insight into how women cope with their worry of cancer recurrence following treatment. Implications of this exploration include

identification of quality of life areas associated with higher levels of worry of recurrence as targets for intervention.

*Physical wellbeing.* The impact of cancer treatment on physical wellbeing appears to be well researched. Many symptoms persist over the long term impacting the quality of life of breast cancer survivors (Ferrell, Funk, Garcia, Grant, & Otis-Green, 1997). These physical outcomes of breast cancer and treatment include pain, hair loss, nausea, lymphedema, skin changes, fatigue, mucositis, menopausal symptoms, weight gain, and fertility and reproductive changes (Ferrell et al., 1997; McDaniel & Rhodes, 1995). Pain has been described as the most debilitating outcome of breast cancer impacting quality of life, particularly the pain associated with breast cancer treatment (Miaskowski & Dibble, 1995). Fatigue is an additional problem for women creating limitations for women in many aspects of their lives including socially and within their work environment (Hanson Frost et al., 2000). This is often compounded by the emotional costs of coping with treatment and the impact of cancer itself on the body (Hanson Frost et al., 2000).

Given the physical outcomes in women with breast cancer highlighted in the literature, it is likely that a relationship will be uncovered between women's physical wellbeing and their level of worry of recurrence in the current study. Underlying this relationship may be current physical symptoms being perceived as indicators of a recurrence or women being worried about a recurrence due to their previous experiences of cancer and treatment related symptoms.

*Social and role functioning.* Breast cancer also has impacts on the social and role functioning domains of women's quality of life. Challenges presented for women within the family context include the impact of a cancer diagnosis on children, worry of future breast cancer in daughters and the burden of a cancer diagnosis on the family (Reele, 1994). Within the spousal relationship, women report communication difficulties, partners feelings of

hopelessness and problems with sexuality including lack of confidence due to loss of a breast, vaginal symptoms or menopausal symptoms relating to cancer treatment (Ferrell et al., 1997). In terms of work, women reported difficulties continuing employment and challenges returning to work and adjusting to normal functioning post treatment (Carter, 1994). Despite these negative effects of cancer on social functioning, women also reported the positive outcomes of social support from peers on their quality of life (Ferrell et al., 1997). There were also financial difficulties arising for women who could not maintain employment as a consequence of their cancer and difficulties relating to relying on their spouses and other family members for financial assistance (Hassey Dow, Ferrell, & Leigh, 1996).

There is also evidence suggesting that differences in wellbeing exist for women dependant on their phase of breast cancer. A study by Hanson Frost and colleagues (2000) examined quality of life differences in women at various phases of breast cancer namely: newly diagnosed women within 6 weeks of diagnosis; an adjuvant group comprised of women receiving either chemotherapy or tamoxifen treatment who were between 6 weeks and 6 months post diagnosis; and a stable group of breast cancer survivors who had not experienced a cancer recurrence and who were at least 6 months post-diagnosis. Outcomes indicated that newly diagnosed and adjuvant groups experienced more difficulties with work and other roles than the stable group due to poorer physical and emotional health. The authors suggested that this was likely relating to women in the newly diagnosed and adjuvant groups attempting to maintain all of their roles. Breast cancer survivors in the stable group were also found to experience fewer problems with fatigue, physical functioning, social functioning and energy. However it is important to point out that breast cancer survivors in the stable group still experienced significantly greater difficulties with fatigue and social functioning than women in the general population. Improvements in functioning over time have also been

established in a study by King and colleagues (2000) which found improvements in women's emotional, social and role functioning, as well as breast cancer related symptoms between 3 months and a year post treatment.

In general, women's experiences of the impact of a cancer diagnosis on their roles including those with their spouse and maintaining employment are likely to influence their worry of a recurrence. More specifically, recurrence worry may be influenced by concerns of how they would cope with these challenges in future. As a consequence, it is expected that that poorer role functioning will be associated with higher levels of worry of recurrence in the current study.

*Body image issues.* Body image issues impact women's quality of life particularly following chemotherapy and hormonal treatment. This includes problems associated with libido, fertility, early menopause and hair loss which are serious threats to body image and femininity (Oktay, 1998). While some studies have indicated fewer body image issues for women who have undergone more conservative breast surgery as opposed to those who have opted for a mastectomy, worries of recurrence are suggested to be more of a concern for these women post treatment (Harrison & Maguire, 1994). Frequent challenges are also presented for marital relationships including communication problems and difficulties coping with sexual dysfunction; in some instances breast cancer becomes too stressful for the couple to cope with (Oktay, 1998). One study indicated that marital quality significantly impacted women's quality of life following breast cancer (Zahlis & Shands, 1991).

It is postulated that body image issues experienced by women following treatment is likely to impact their worry of cancer recurrence. This may be related to women's concerns of the impacts of future treatments on their fertility, intimate relationships, physical attractiveness and femininity. As a consequence, it is likely that poor body image may

contribute to a relationship between poorer quality of life in breast cancer survivors and greater worry of recurrence.

### *Psychological wellbeing in breast cancer survivors*

Psychological wellbeing can be defined as "seeking a sense of control in the face of life threatening illness characterized by emotional distress, altered life priorities, and worries of the unknown" (Ferrell et al., 1998, p. 1). The psychological wellbeing of women is frequently impacted by breast cancer with research indicating significant levels of distress in women post breast cancer treatment (Glanz & Lerman, 1992). This has been attributed to many factors including worries of recurrence, loss of support, reduced contact with medical professionals (Rowland, 1999), the meaning of physical symptoms, the potential impacts of chemotherapy treatment, body image issues, arm pain, swelling and the social stigma of having cancer (Wong & Bramwell, 1992). The importance of reviewing literature pertaining to the psychological wellbeing of breast cancer survivors is related to research highlighting worry of recurrence as a significant underlying factor of distress and poorer psychological outcomes in this population (Ferrell et al., 1998; Fredette, 1995).

*Anxiety and depression.* The prevalence of anxiety and depression in women with breast cancer is approximately double that of women in the general population (Burgess et al., 2005), however some studies estimate that approximately 60.0% of women experience significant anxiety post breast cancer treatment (Trief & Donohue-Smith, 1996). Other research indicates that between 10.0 to 25.0% of women experience depression (Fann et al., 2008) and 11.0% of women meet criteria for Major Depressive Disorder following treatment (Hegel et al., 2006). A study by Burgess and colleagues (2005) of 222 women up to 5 years post treatment found that the incidence of anxiety and depression in breast cancer survivors halves in the 2<sup>nd</sup>, 3<sup>rd</sup> and 4<sup>th</sup> years post diagnosis, decreasing even further to 15.0% of women experiencing either disorder after 5 years.

*Post traumatic symptoms.* In addition, a study by Tjemsland and colleagues (1998) found that approximately 12.0% of breast cancer survivors also meet criteria for post traumatic disorder a year post surgery, with 9.0% of women experiencing intrusive symptoms and 10.0% reporting avoidance symptoms. Common symptoms included sleep difficulties because of “pictures or images about the illness coming to mind”, bad dreams relating to the cancer experience and avoidance of subjects relating to breast cancer (Tjemsland, Søreide, & Malt, 1996, p. 144). The severity of post traumatic symptoms was associated with high emotionality reactivity, poor psychosocial functioning and negative life events in the year prior to surgery and health issues during the decade preceding cancer treatment. However, adjuvant chemotherapy, surgery type and disease staging were found to have no impact on post traumatic symptoms post-surgery (Tjemsland et al., 1996).

*Risk Factors.* Risk factors pertaining to the individual have been suggested to increase women’s risk of anxiety and depression post treatment. These include risk factors for anxiety and depression in the general population of younger age (Simonton & Sherman, 1998), prior psychological difficulties, life stresses and lack of social support (Harrison & Maguire, 1994). In addition, these factors and more specifically a lack of a close confiding relationship have been associated with long term psychological morbidity and a greater number of prolonged episodes of anxiety and depression in breast cancer survivors (Burgess et al., 2005). The psychological state of the individual prior to diagnosis has also been highlighted as a significant predictor of psychological adjustment post treatment (Carlsson & Hamrin, 1994) while variables including prognosis, breast surgery type and radiotherapy adjuvant treatment have been found to not influence risk (Burgess, Ramirez, Richards, & Potts, 2002). On the other hand, chemotherapy has been associated with higher levels of anxiety and depression, and poor health related quality of life in women with breast cancer (Hughson, Cooper, McArdle, & Smith, 1986; Longman, Braden, & Mishel, 1999; Schagen et al., 1999).

In relation to hormonal treatment, the association between tamoxifen treatment and depression is mixed, with some studies indicating a link (Thompson, Spanier, & Voge, 1999) and others suggesting no association (Lee, Ray, Hunkeler, & Finley, 2007). There is also little evidence suggesting that cancer staging has any impact on levels of depression post treatment (Kissane et al., 2004).

*Protective factors.* Protective factors against anxiety and depression include the communication style of the breast surgeon and dissemination of information (Harrison & Maguire, 1994). For women who have been given a choice of conservative treatment or mastectomy, levels of anxiety and depression decreased over the 2 month period post-treatment (Morris & Royle, 1988). The importance of information giving was also highlighted in a study by Rainey (1985) which found better psychological outcomes in women who had received detailed information about their radiotherapy treatment as opposed to women who had undergone routine care. Overall, the psychological distress women experience post diagnosis has been found to remain fairly constant in the year following diagnosis (Nosarti, Roberts, Crayford, McKenzie, & David, 2002)

### ***The role of trait anxiety on quality of life and psychological wellbeing***

Trait anxiety may be described as a relatively stable personality trait that accounts for the level of anxiety exhibited when the individual encounters difficulty (Spielberger, Gorsuch, & Lushene, 1970). It has been identified as a vulnerability factor for developing depression during periods of adversity or stress (Sandi & Richter-Levin, 2012).

Trait anxiety was also found to predict women's quality of life post treatment. A study by Weitzner and colleagues (1997) which investigated quality of life in long term breast cancer survivors and low risk breast cancer screening patients found that trait anxiety was a significant predictor of quality of life in both groups including health functioning, socioeconomic aspects, psychological wellbeing and the spiritual domains of quality of life.

The impacts of trait anxiety on aspects of quality of life were also highlighted in a study by Lockefer and De Vries (2012) of 163 breast cancer patients and 224 women with benign breast problems. It was found to be the most significant predictor of depressive symptoms, fatigue, and poor sleep quality in both groups, and appeared to play a role in the persistent nature of these problems at the 2 year follow up. Overall, it has been indicated it is imperative that trait anxiety be included in future studies of quality of life in cancer patients to “characterize their quality of life more completely” (Weitzner et al., 1997, p. 246).

The associations between trait anxiety and worry of recurrence will be investigated in the current study. Given trait anxiety has been highlighted as a predictor of depression, anxiety and poorer quality of life, it is expected that higher levels of trait anxiety will be associated with greater worry of recurrence. Also, as suggested by Weitzner (1997), trait anxiety will be included in the current study as a covariate in investigations of the relationship between all domains of quality of life including psychological adjustment and levels of worry of cancer recurrence.

## **Section 2. The Relationship between Worry of Cancer Recurrence and Age**

Elucidation of the relationship between age and worry of recurrence may be crucial for identification of women at risk of higher levels of cancer worry and therefore poorer psychological adjustment. It may also provide further support of the need for interventions targeting specific difficulties or concerns underlying women’s cancer worry at different life stages. According to Rowland (1989), adult life stages relevant to a diagnosis of breast cancer include the mature adult (31-45), the middle aged adult (46-65) and the aging adult (>65).

The literature on breast cancer survivors has consistently highlighted better psychological adjustment in older women than younger women post breast cancer treatment (Bloom, Stewart, Chang, & Banks, 2004; Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998). For example, a study by Ganz and colleagues of breast cancer survivors who were an

average of six years post diagnosis, indicated the poorest social and emotional functioning for women aged between 24 and 34 (Ganz, Grendale, Peterson, Kahn, & Bower, 2003). These findings were replicated by King and colleagues (2000) investigated quality of life in 305 breast cancer survivors at 3 months and 1 year following treatment for primary breast cancer. Quality of life was evaluated across several domains including global quality of life, physical functioning, role functioning, social functioning, emotional functioning and cognitive functioning. Older women exhibited better global, social and emotional functioning, better body image and less pain than younger women. In relation to body image, younger women and those in romantic relationships placed greater importance on their breasts, femininity and their attractiveness. Overall, most studies indicate that older breast cancer survivors appear to exhibit better overall functioning in most areas of quality of life including social functioning and mental health (Vinokur, Threath, Vinokur-Kaplan, & Satariano, 1990).

Given research highlighting cancer worry as a significant contributor to poorer psychological outcomes in breast cancer survivors (Ganz et al., 1996), it is likely that a similar association exists between women's age and their level of cancer worry post treatment. However, despite worry of cancer recurrence being a predominant concern for many women, fewer studies have examined the association between age and worry of cancer recurrence specifically. However on inspection of the existing research, most studies investigating this association indicated a similar relationship, with younger women experiencing higher levels of cancer recurrence worry compared to older women (Mast, 1998; Ziner, Sledge, Bell, Johns, Miller, & Champion, 2012). Exceptions to this includes a study by Cimprich and colleagues (Cimprich, Ronis, & Martinez-Ramos, 2002) which found no difference in levels of cancer worry between participants diagnosed under 45 years of age, between 45 and 64, and those over 65.

Overall, age disparities in adaptation post cancer treatment have been attributed to the impact a cancer diagnosis has on women's ability to fulfil the different demands and roles they encounter at their specific life stages (Cimprich et al., 2002). More specifically, greater distress in younger breast cancer survivors may be related to having multiple responsibilities including those relating to caring for children, being a spouse, having a career, the threat of early death and a poorer ability to cope with a major illness (Kornblith, 2007). A recent study compared recurrence worries in survivors who were diagnosed with breast cancer under the age of 45 to those diagnosed at 55 to 70 years of age (Ziner et al., 2012). Findings appeared to corroborate the link between life stage worries and age, as younger women were found to have higher levels of recurrence worry and specific worries about recurrence relating to death, health, role and parenting concerns. This was further illustrated by Vickberg (2003), who found that age was the strongest predictor of worries of recurrence, with younger women having greater recurrence worry across all life domains.

While existing studies appear to indicate an association between age and worry of recurrence, a current understanding of whether there are age differences in how women cope with worry of recurrence is warranted to further our understanding of the relationship between age and recurrence worry. This association will be examined in the current investigation using the newly developed 'Coping with Worry of Cancer Recurrence Measure'.

### **Section 3. The Impact of Cancer Treatment on Worry of Cancer Recurrence**

Including age at diagnosis, initial treatment is also likely to impact women's worry of cancer recurrence (Vickberg, 2001). An understanding of the influence of treatment on worry of recurrence is important for early identification of women undergoing specific types of treatment which may be associated with an increased risk of elevated levels of worry of recurrence and related psychological distress. The current study focuses on the impacts of

adjuvant treatment, specifically chemotherapy, hormone therapy and radiotherapy on levels of cancer worry. Given the persistent and late effects of adjuvant treatment highlighted in the literature (Knobf, 2006) treatment type is hypothesized to influence women's levels of cancer worry post treatment. Thus far, literature pertaining to the relationship between adjuvant treatment and worry of recurrence is minimal to nonexistent. However, previous research has focused on the impacts of adjuvant treatment on women's overall adjustment and quality of life. As such, the following review focuses on the impacts of adjuvant treatment on quality of life and emotional functioning, and given that both factors are linked to worry of recurrence, it is likely that similar associations between adjuvant treatment and recurrence worry will be uncovered in the current investigation.

#### ***Symptomatic and functional effects of adjuvant treatment***

Adjuvant treatments are often used to treat specific symptoms and to reduce women's risk of cancer recurrence post-surgical treatment. A study conducted by Shover and colleagues (Schover, Yetman, Tuason, Meisler, Esselstyn, & Hermann, 1995) found significantly worse adjustment in women who had received chemotherapy treatment compared to other treatments, including poorer body image and more sexual problems. Sexual difficulties for women in the study included being less sexually active, less satisfied with their sex lives, experiencing greater difficulties reaching orgasm and problems with intercourse due to vaginal dryness. Chemotherapy has also been linked to pre and peri-menopausal women transitioning into early menopause, experiencing amenorrhea and hot flashes (Ganz et al., 1996). Knobf (2006) proposes that while younger women had a lower risk for amenorrhea with adjuvant chemotherapy, they were at higher risk of earlier menopause than otherwise expected (Knobf, 2006). Overall, early menopause due to chemotherapy is associated with poorer sexual functioning, distress related to fertility concerns and menopausal symptoms (Knobf, 2006).

However, a further study indicated adjustment difficulties for women not only receiving treatment for chemotherapy, but also for those receiving hormonal treatment (Ganz et al., 1996). The study indicated that while tamoxifen treatment was better tolerated than chemotherapy, it was also associated with vaginal dryness, itching and discharge; menstrual problems, hot flashes and sexual difficulties. Other problems or symptoms associated with hormonal treatment include insomnia, weight gain, joint pain, fatigue, depression and hair loss (Ganz, 2001; Ganz et al., 2003). With regards to radiotherapy, women who opt to undergo lumpectomy surgery as opposed to a mastectomy following breast cancer diagnosis are often faced with the option of having adjuvant radiotherapy (Lee et al., 2008). Women's concerns related to radiotherapy treatment include swelling and pain at the treatment area, skin irritation and generalised fatigue (Back, Ahern, Delaney, & et al, 2005). Other rarer side effects include a secondary malignancy (Yap, Chuba, & Thomas, 2002) and heart disease (Giordano, Kuo, Freeman, & et al, 2005).

#### ***Adjuvant treatment and quality of life***

On overall inspection of the literature, chemotherapy, and hormonal treatment to a lesser extent, appears to play a major role on women's adjustment and quality of life post breast cancer treatment. It appears that while adjuvant treatments have prolonged survival, women's quality of life is impacted by later effects of adjuvant treatment (Knobf, 2006). Chemotherapy in particular has been found to be a strong predictor of poorer quality of life in breast cancer survivors over the long term (Amir & Ramati, 2002; Mols, Vingerhoets, Coebergh, & et al, 2005; Schover, Yetman, Tuason, Meisler, Esselstyn, & Hermann, 1995). Overall, the literature on women's quality of life post adjuvant radiotherapy treatment is very limited. Examination of studies pertaining to radiotherapy treatment with Cobalt-60 machines indicated either no difference in quality of life between women receiving radiotherapy and those who did not at 3, 6 and 12 months post-surgery (Rayan, Dawson, Bezjak, & et al,

2003), or a lower quality of life between each group at 1 and 2 months post-surgery (Whelan, Levine, Julian, & et al, 2000). Research using more current methods of radiotherapy indicated improvements in quality of life post treatment (Wengstrom, Haggmark, Strander, & et al, 2000) or no difference in quality of life at baseline, completion and 7 months post radiotherapy treatment (Lee et al., 2008). For the latter study, the most debilitating symptoms of radiotherapy, namely fatigue and breast symptoms were found to return to baseline levels 7 months post radiotherapy.

### *Adjuvant treatment and worry of recurrence*

One of the few studies to establish a link between cancer treatment and worry of recurrence, was by Vickberg (2001) who investigated the nature of women's recurrence worries. The investigator found that having to undergo chemotherapy again was the second most common recurrence worry for breast cancer survivors, the most common worry being death. This appeared related to women being averse to enduring the side effects of chemotherapy treatment and worrying they would be unable to cope with it again. Similarly, a further investigation found higher levels of recurrence worry in women who had undergone chemotherapy in comparison to those who received other adjuvant treatments (Schover, Yetman, Tuason, Meisler, Esselstyn, Hermann, et al., 1995).

Overall, research to date appears to indicate that both chemotherapy and hormonal treatment are associated with poorer quality of life, with the literature also highlighting a link between chemotherapy and higher levels of worry of recurrence. However, the impact of radiotherapy and hormonal treatment on worry of recurrence in breast cancer survivors has not been evaluated. As a consequence, the current investigation will examine the relationship of all three adjuvant treatments with women's levels of recurrence worry post treatment. The mechanisms by which treatment type influences women's worry of recurrence may include: women's existing symptom experiences which are perceived as indicators of a current cancer

recurrence; or women's worry of undergoing treatment again in the premise of a recurrence, due to past treatment experiences of unpleasant symptoms and its impacts on their wellbeing. Given the associations highlighted in this review, namely the persistent and aversive symptoms associated with chemotherapy and hormonal treatment and its impact on women's quality of life, it is expected that both chemotherapy and hormonal treatment will be associated with higher levels of worry of recurrence.

#### **Section 4. Worry of Cancer Recurrence and Women's Wellbeing**

The following section presents research relating to four areas including: the relationship between time since diagnosis and worry of recurrence; studies that have identified worry of recurrence as a factor underlying psychological distress; research examining the meaning of worry of recurrence for breast cancer survivors; and studies that have investigated the association between worry of recurrence and quality of life, including psychological outcomes in women with breast cancer. Overall, this review highlights the need for a better understanding of worry of cancer recurrence due to its impacts on the women's wellbeing. The current study aims to further examine this association by investigating the relationship between levels of recurrence worry and time since diagnosis, quality of life, and psychological distress.

##### ***Time since diagnosis and worry of recurrence***

Outcomes of studies investigating the impact of time since diagnosis on levels of worry of recurrence appear mixed. Some studies appear to indicate that worry of recurrence decreases over time (Hughes, 1993) while others suggest that worry of recurrence remains stable, years after treatment (Leake, Gurrin, & Hammond, 2001; Mehta, Lubeck, Pasta, & Litwin, 2003) .

### *Worry of recurrence as a source of distress*

Interestingly, while most research on quality of life in cancer survivors has not specifically focused on the relationship between cancer worries and psychological wellbeing, they have highlighted worry of recurrence as a source of distress. In particular a qualitative study investigating the impacts of breast cancer on the quality of life of survivors uncovered several themes related to worry of cancer recurrence (Ferrell et al., 1998). With respect to women's psychological wellbeing, concern for the future was identified as the first major theme, particularly in relation to worries of dying and challenges of maintaining hope.

Women identified uncertainty about whether their treatment had eliminated all of their cancer as a major source of distress and described strong hopes for new treatments in the event their cancer would recur in future. Similar themes related to cancer worry were uncovered for the spiritual domain of quality of life, with women indicating uncertainty about the future as one of the most challenging aspects of survivorship. These findings were also replicated in an earlier study of 14 women, at least five years post breast cancer treatment (Fredette, 1995).

Worries of cancer recurrence were also identified as a source of ongoing distress for women in research examining the psychosocial concerns and quality of life in breast cancer survivors at 2 and 3 years post treatment for primary breast cancer (Ganz et al., 1996). The study indicated improvements in general quality of life between 1 month and a year following treatment, but no difference in quality of life between 2 and 3 years post treatment. Issues that impacted quality of life immediately following treatment were found to resolve over time including hair loss, fatigue and nausea. However, while survivors exhibited high functioning in certain areas of quality of life over time including role functioning, social functioning, pain and general health, some concerns persisted over time influencing quality of life. These included body image issues, sexual problems, communication with medical professionals, problems with endocrine treatment and worry of recurrence. The authors indicated that

interventions addressing these issues are warranted to improve women's quality of life beyond the first year post treatment. Other research also found a positive correlation between state anxiety and worry of recurrence in breast cancer survivors, with forty eight percent of the cohort experiencing uncertainty as to whether cancer cells were still in the body and "nagging thoughts that the cancer could recur (Wong & Bramwell, 1992, p. 368)."

### ***The meaning of worry of recurrence for breast cancer survivors***

Exploration of research investigating what cancer recurrence means for women highlighted the reasons as to why cancer worries are a major source of distress for survivors. A study of 169 breast cancer survivors found that women's worry of cancer recurrence was related to the possibility of death, undergoing future treatment, physical limitations arising from the cancer and treatment, and emotional difficulties (Vickberg, 2003). Surprisingly, issues relating to sexuality, femininity, body image or life roles did not underlie women's recurrence worries. These findings replicated an earlier study by Vickberg (2001) which highlighted additional worries propagating women's concerns of recurrence including women's worry of pain, advancement of disease, loss of a breast and suffering of family.

Overall, death was cited as the most predominant concern motivating recurrence worry. Related to this were women feeling they were not ready to die or to leave loved ones behind, and their worry of being unable to watch their children grow. Similar findings were reported by Oktay (1998, p. 7) who described women struggling with questions related to their children including, "what should I tell them?", "do I have the resources to fight this disease and to continue to parent my children at the same time?", "how will this affect their growth and development?" and "what will happen to them if I die ?" Additionally, survivors have also mentioned being fearful of not being able to live out their lives with their partner (Spencer et al., 1999).

Triggers of recurrence worries were also investigated in Vickberg's study (2003) with 'being around others with cancer' or 'hearing about cancer' identified as the most common triggers of worry of recurrence. In some cases, interaction with women who had undergone mastectomies caused participants to consider if their conservative treatment choices were wise. The second most common trigger was doctor's appointments or mammograms, or in other words situations which could identify an actual recurrence. Other triggers included physical reminders of the cancer including pain, while future orientated activities, for example making large purchases, caused women to question if they would be alive to enjoy them. Overall, given the nature of women's worry of cancer recurrence, the negative impact of cancer worry on women's psychological wellbeing and quality of life is not surprising. However it should be noted that few studies have conducted an in-depth analysis of this relationship.

***The relationship between worry of recurrence and quality of life, and psychological wellbeing***

Research examining the relationship between cancer survivors' worries of cancer recurrence and psychological wellbeing or quality of life is sparse, despite many women reporting the impact of cancer worry on their adjustment and quality of life (Cimprich et al., 2002; Hart, Latini, Cowan, Carroll, & Investigators, 2008). More specifically, breast cancer survivors report that worry of recurrence dramatically reduces their global sense of wellbeing and enjoyment of life (Cimprich, Ronis, & Martinez-Ramos, 2002; Spencer et al., 1999).

Existing studies investigating the link between cancer worry and psychological morbidity have indicated associations between depression and anxiety, the most predominant psychological disorders in breast cancer survivors, and worry of cancer recurrence (Schidmit-Bu'chi, Halfens, Dassen, & Van den Borne, 2008; Vickberg, 2001). Furthermore, research has suggested that higher levels of recurrence worry is associated with a worse quality of life

(Mellon, Northouse, & Weiss, 2006), more checking of bodily symptoms, hopelessness (Lee-Jones, Humphris, Dixon, & Hatcher, 1997), greater psychological distress (Humphris et al., 2003) and panic attacks (Wong & Bramwell, 1992).

A recent investigation of the link between worry of recurrence and anxiety and depression in orofacial cancer survivors found clear associations between cancer worry and psychological morbidity (Humphris et al., 2003). Overall, findings suggested that recurrence worry was more closely associated with anxiety over the long term, although a strong association between cancer worry and depression was also indicated in the early stages following cancer treatment. The authors surmised that recurrence worry was relatively stable for cancer survivors over time and may have repercussions for the psychological wellbeing of individuals if they remained at a consistently high level. Similar findings were uncovered in an investigation of 455 cancer survivor-caregiver dyads which indicated an association between higher levels of cancer worry and poorer mental and physical quality of life, even after taking into account survivors' levels of general anxiety (Kim, Carver, Spillers, Love-Ghaffari, & Kaw, 2012). These findings were further supported during validation of the Concerns of Cancer Recurrence Scale (Vickberg, 2003). All subscales comprising the measure were found to be significantly positively correlated with intrusive thoughts, avoidance behaviour and distress in breast cancer survivors and negatively associated with their overall wellbeing. In relation to Post Traumatic symptomology, a study of 1083 breast cancer survivors an average of 47 months post diagnosis found that moderate to high levels of worry of recurrence were positively associated with intrusions, avoidance and hyperarousal (Mehnert, Berg, Henrich, & Herschbach, 2009).

While these studies indicate a relationship between women's worries of cancer recurrence and quality of life including psychological wellbeing, few studies have examined the association between levels of cancer worry and quality of life across several domains

including general health, physical functioning, bodily pain, vitality, physical and emotional roles and mental health. The current study will explore these relationships and extend previous research by examining the association between cancer worry and levels of depression, anxiety, and post traumatic symptoms in New Zealand women post treatment for primary breast cancer. In addition, the roles of age, trait anxiety, treatment type and time since diagnosis will also be evaluated in relation to how they may influence associations between women's worry of recurrence and their wellbeing. It was noted that few studies have accounted for these factors in investigations of this association.

### **Section 5: Illness Representations and the Self-Regulation of Worries of Recurrence**

A greater understanding of women's adjustment post treatment and their worry of cancer recurrence may be obtained by examining their perceptions or appraisals of breast cancer. Individuals often form mental schema or representations of their illness which influences their emotional distress and guides coping responses (Cameron & Leventhal, 2003). The representations of breast cancer held by survivors have been found to vary considerably predicting differences in quality of life, emotional distress and coping responses (Buick, 1997; Cameron, Booth, Schlatter, Ziginskis, & Harman, 2007; Cameron et al., 2005). One of the aims of the current study is to examine the association between women's representations of breast cancer including their mental image of cancer and their levels of recurrence worry post treatment. It is likely that a greater understanding of this relationship may help elucidate differences between individuals in terms of how their illness representations predict worries of recurrence post treatment. This may be especially important in guiding future psychological interventions aimed at reducing psychological morbidity in breast cancer survivors. The theoretical framework used to understand women's breast cancer representations in the current study is Leventhal's Self-Regulation Model of

Illness (Leventhal et al., 1997; Leventhal, Nerenz, & Steele, 1984), often referred to as the Common Sense Model.

### *The Common Sense Model of Self Regulation*

Leventhal's Common Sense Model of Self-Regulation conceptualises how individuals view their illness, understand it and cope with it (Leventhal, Brissette, & Leventhal, 2003). Illness representations can also be understood as an individual's ideas and expectations of their illness and bodily symptoms. This self-regulation model can be viewed as a parallel processing framework whereby the abstract–conceptual processes (e.g., cognitive beliefs and reasoned problem-solving) operate in parallel with concrete –experiential processes (e.g., memories, mental images, and somatic perceptions) in both cognitive and emotional domains (Epstein, 1994). In other words, individuals simultaneously process and create emotional and cognitive representations of their disease. Cognitive and emotional representations are highly linked, with reciprocal influences such that cognitive beliefs about the nature of the illness influences emotional distress which, in turn, guides information processes that shape the updating of cognitive beliefs. According to Leventhal and colleagues (Leventhal et al., 2003; Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984), illness representations are derived and influenced by three different sources of information. The first is described as general information that one gathers from communicating with others and from cultural knowledge of the disease. The second type of information is gained from figures of authority or individuals of influence such as medical professionals or one's parents. The third source of information impacting an individual's illness representation is derived from their own illness experience. This includes one's experience of the symptomology of the illness as well as the efficacy of coping strategies they have implemented.

Representations are comprised of five attributes: identity (the number of symptoms perceived to be related to the condition), cause (the individual's perception of the

cause/causes), timeline (beliefs related to the time of occurrence and duration of the illness and its associated symptoms), consequences (beliefs about severity, possibility of death and the impact of the disease on their physical, psychological, emotional, economic and social functioning) and control/cure (beliefs relating to the controllability of the disease) (Leventhal et al., 2003).

Emotional representations are comprised of perceptions of the emotional consequences of the illness (Leventhal et al., 2003; Moss-Morris et al., 2002). In the context of breast cancer, these emotional representations typically include worries about recurrence (Cameron, 2003). Studies have emphasized the influence of cognitions and emotional representations including worry of recurrence on psychological adjustment, health protective behaviours, coping and complying with medical advice (Anagnostopoulos & Spanca, 2005; Cameron, 2003; Leventhal et al., 2003; Millar, Purushotham, McLatchie, George, & Murray, 2005).

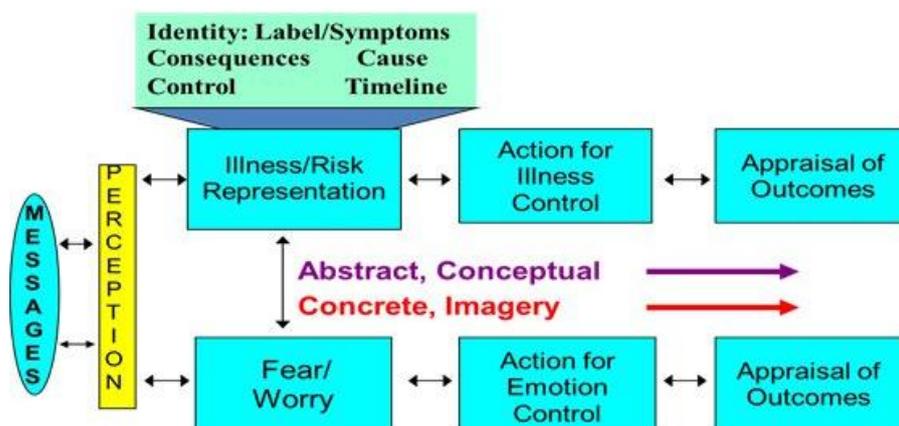


Fig 1. *The Common Sense Model of Self Regulation adapted from Cameron and Moss-Morris (2010)*

### ***Roles of illness representations***

Figure 1 presents the role of illness representations in managing health threats including the selection and appraisal of coping strategies aimed at reducing risk. It illustrates

how exposure to stimuli (eg. symptoms) activates illness representations which may include the matching of symptoms to an illness label. This process of matching symptom experiences and contextual information with pre-existing beliefs of the illness results in construction of mental representations of the individual's current condition, including their level of risk. Coping efforts to alleviate the health threat are then guided by these representations and continually appraised and modified dependent on their ability to manage the health threat and its related outcomes.

Messages of health threat including symptoms not only trigger the activation and construction of cognitive representations, but also emotional representations including responses of worry. While illness representations elicit emotions including distress, similarly, emotional representations including worry can impact cognition by influencing how illness cues or symptoms are interpreted. Emotional representations of worry have been suggested to significantly impact illness beliefs and protective behaviours (Cameron & Chan, 2008). According to Cameron and Moss-Morris (2010) the influence of worry promotes rumination about illness, the development of extensive illness beliefs and heightened accessibility to illness representations, which in turn increases motivation to engage in protective behaviours.

A combination of emotional representations and cognitive representations can also exacerbate emotional responses; for example the discovery of a lump may trigger worry, while also activating illness representations matching the symptom to the 'cancer' label, producing heightened emotions of worry. Coping strategies to alleviate emotional distress are then implemented, appraised and adjusted dependent on their efficacy at managing distress.

It is suggested that groups of beliefs rather than individual representations influence illness outcomes (Cameron & Moss-Morris, 2010). Illness coherence refers to the degree to which groups of illness beliefs are linked to allow the individual to make sense of their condition, and also the extent to which these group of beliefs are logically associated with

coping behaviours (Cameron & Moss-Morris, 2010, p. 156). Research indicates that individuals often develop representations of connected beliefs, for example a more chronic timeline and a large number of symptoms is often associated with beliefs of lower illness control and more severe consequences.(Moss-Morris et al., 2002).

The use of appropriate protective behaviours or coping strategies is dependent on the linking of illness representations to these coping strategies; essentially individuals must be aware of how their coping behaviours will manage their health threat. The importance of this link was demonstrated in a study where participants who were educated on how smoking damages cells and increases risks of cervical cancer, were more motivated to quit smoking (Bishop, Marteau, Hall, Kitchener, & Hajek, 2005).

### ***Emotional regulation within the context of Common Sense Model***

Following an individual's awareness of their emotional reaction to an illness threat, are efforts directed at controlling these emotions. These may include reactions of avoidance, focus, expression or suppression of emotions, or positive reappraisal (Cameron & Moss-Morris, 2010). Figure 2 presents an extension of the Common Sense Model which includes key emotional regulation strategies of: (1) attentional deployment strategies including avoidance or the focusing of attention on the threat; (2) proactive behaviours to alleviate threat; (3) reappraisal or cognitive change; (4) and emotional modulation (e.g. suppression, relaxation, substance use" (Cameron & Jago, 2008). The model also presents problem solving strategies pertaining to the cognitive arm of the model implemented to control the illness, including strategies of using medical treatments, seeking further information and adopting healthier behaviours. Overall, the extended model highlights the interdependence of problem focused and emotion focused coping, ultimately strategies used to control illness impacts emotional regulation and vice-versa.

A meta-analytic investigation of 45 studies utilising the Common Sense Model provided empirical support for the use of the model in predicting coping responses and outcomes in individuals with various conditions including cancer, HIV and Addison's disease .(Hagger & Orbell, 2003). Specific patterns of association were uncovered in this investigation including a significant positive relationship between a strong illness identity and strategies of avoidance and expression. Controllability beliefs were related to use of cognitive reappraisal, problem focused coping and expression, while a chronic timeline and serious consequences were found to be correlated with avoidance and expression. With respect to the relationship between illness representations and health outcomes, beliefs of cure/control were positively associated with psychological wellbeing, vitality and social functioning, and negatively related to distress. Conversely, perceptions of more severe consequences, a chronic timeline and a strong illness identity were linked with poorer psychological wellbeing, functioning and vitality. It is expected that similar patterns of associations between women's illness beliefs and worry of recurrence will be uncovered in the current investigation of breast cancer survivors.

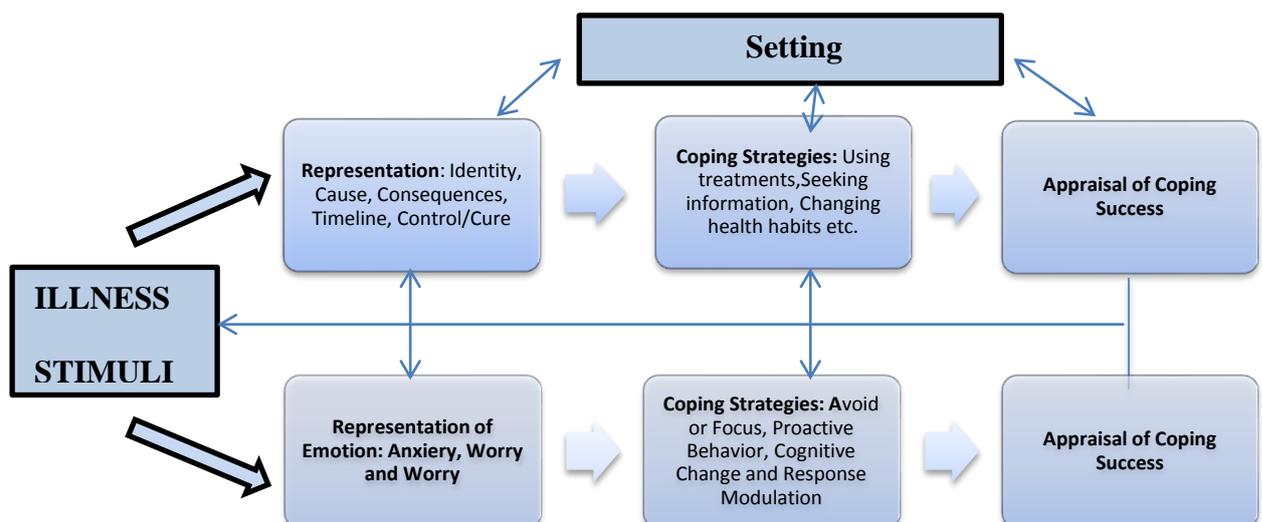


Fig 2. The common-sense model of the self-regulation of illness behaviour, with the elaboration of emotion-focused coping to include four emotion regulation strategies adapted from Cameron and Jago (Cameron & Jago, 2008, p. 216)

### *Assessment of illness and emotional representations*

Illness representations have been measured with a variety of techniques, including qualitative methods (Green, Payne, & Barnitt, 2004) and structured interviews (Cameron, Leventhal, & Leventhal, 1993; Cameron, Leventhal, & Leventhal, 1995). However, recently researchers have relied predominantly on the Illness Perceptions Questionnaire (IPQ) and the Illness Perceptions Questionnaire Revised (IPQ-R) to evaluate illness representations in various populations.

The Illness Perceptions Questionnaire (IPQ) was initially developed to assess illness representations as delineated by the five cognitive attributes delineated by the Self-Regulation model (Weinman, Petrie, Moss-Morris, & Horne, 1996). A revised version, the Illness Perceptions Questionnaire-Revised (IPQ-R) (Moss-Morris et al., 2002) includes 3 additional subscales assessing emotional representations (emotional responses to the disease), coherence (understanding of the illness) and timeline cyclical (the unpredictability or changeable nature of the disease/symptoms). In addition, the control/cure dimension has been divided into 2 separate subscales labelled personal control and treatment control. The IPQ-R has been validated in studies of individuals with various conditions including chronic and acute pain, rheumatoid arthritis, HIV, multiple sclerosis, diabetes, asthma and myocardial infarction (Moss-Morris et al., 2002).

Further developments of the IPQ-R approach to measuring illness representations led to the Assessment of Illness Risk Representations (AIRR) (Cameron, 2008), which expanded the scope of measurement to include a subscale assessing mental images stored within the representation. Mental images identified using this subscale have been found to uniquely predict emotional and behavioural responses to health threats, including skin cancer risk (Cameron, 2008) and heart disease risk (Lee, Cameron, Wünsche, & Stevens, 2011).

Significant strong correlations between dimensions of the Self-Regulation Model have been found in studies of various illness populations (Heijmans, 1999; Heijmans & De Ridder, 1998; Weinman et al., 1996). More specifically, these studies demonstrated that the identity dimension was strongly negatively correlated with the cure/control dimension and positively correlated with perceptions of a more chronic timeline and serious consequences of the disease. In other words, individuals who reported experiencing more disease related symptoms also viewed their illness as more uncontrollable, chronic and having more serious consequences on their lives. On the other hand, individuals who perceived having greater control over their illness also construed their condition as being less chronic and with fewer serious consequences

#### ***Illness representation dimensions and worry of cancer recurrence***

Illness beliefs have been associated with greater psychological morbidity, including the maintenance of anxiety and depression in a variety of different diseases (Houldin, Jacobsen, & Lowery, 1996; Murphy, Dickens, Creed, & Bernstein, 1999). With regards to overall wellbeing, a meta-analysis of empirical studies using the Self-Regulation Model of Illness Representations found that beliefs of greater illness cure/control were significantly positively associated with better outcomes on measures of vitality, social functioning and psychological wellbeing and negatively correlated with distress (Hagger & Orbell, 2003). On the other hand, findings indicated that scores pertaining to the identity, timeline and consequences dimensions were significantly negatively related to psychological wellbeing, vitality and role and social functioning. Despite promising evidence in other illness domains, few studies have examined the link between illness perceptions relating to the duration (timeline) of the illness, emotional reactions (emotional representation), symptom awareness (identity), the controllability/curability of the disease, illness coherence, illness consequences and the unpredictability of symptoms, on levels of recurrence worry in breast cancer

survivors. A review of the findings of the existing literature on the relationship between illness representations and worry in various disorders, including cancer, is presented below.

*Identity beliefs.* Physical symptoms may serve to remind individuals of their cancer and be perceived as an indicator that the disease has returned, activating worries of recurrence (Lee-Jones et al., 1997). It has been suggested that highly anxious individuals are likely to be more vigilant to somatic cues, often labeling and identifying symptoms that may be unrelated to the disease (Salkovskis, 1989). A study of quality of life and recurrence concerns found that reports of persistent symptoms of pain and disfigurement were associated with higher levels of worry of recurrence in survivors of head and neck cancer (Campbell, Marbella, & Layde, 2000). Similar associations were found in a study by Mellon and colleagues (2007) investigating factors associated with worry of recurrence in survivors of various cancers including breast, prostate, colon and uterine cancer. A study by Skaali and colleagues (2009) of survivors of testicular cancer found that reports of one or more severe somatic symptoms were significantly associated with levels of worry of recurrence in the year following cancer treatment. These findings pertaining to the relationship between illness identity and worries of recurrence have been replicated in studies examining this association in breast cancer survivors, including that conducted by Mathews and colleagues (2002) which found that survivors who reported greater somatic symptoms also experienced overall poorer adjustment post treatment.

*Consequences and emotional representations.* A study by Llewellyn and colleagues (2008) of head and neck cancer survivors, indicated that higher levels of recurrence worries were associated with beliefs of more severe disease consequences and stronger emotional representations. Surprisingly, this investigation uncovered no associations between perceptions relating to timeline or identity with worries of recurrence. However, the relationship between consequence beliefs and psychological wellbeing was further

highlighted in a study by Stafford and colleagues (2009) which found associations between more severe consequence beliefs and depressive symptoms in individuals with coronary heart disease at 6 month follow up.

*Timeline beliefs.* While studies investigating the association between timeline beliefs and worries of illness recurrence are mixed, a majority of studies indicate that perceptions of a more chronic timeline are correlated with higher levels of cancer worry. One of few exceptions included an investigation by Millar and colleagues (2005) of the variation in psychological morbidity in 371 breast cancer survivors, in the year following breast cancer surgery. The study found that chronic elevated levels of distress were significantly associated with greater symptom awareness and perceptions of shorter illness duration. The authors hypothesized that the association between perceptions of a more acute disease course and higher levels of recurrence worry was due to women's pessimism about survival. However, in contradiction to the findings of this investigation, earlier predictions suggested that higher levels of worry of illness recurrence would be associated with perceptions of a more chronic timeline rather than a single acute episode (Lee-Jones et al., 1997). This assumption appeared consistent with a study by Rabin and colleagues (2004) of breast cancer survivors indicating that conceptualizations of cancer as a chronic or cyclic illness, as opposed to an acute condition were related to greater levels of cancer worry and distress. The authors hypothesized that this association was due to women believing that "their cancer was hiding somewhere in their bodies only to re-emerge later" (Rabin et al., 2004, p. 411).

*Coherence.* The study by Rabin and colleagues (2004) also suggested that illness coherence may be an important factor impacting women's emotional reactions following treatment for breast cancer. Many women in the study were unable to identify their disease stage or lymph node status, which the authors suggested may be linked to greater levels of distress. Similar associations between poor disease coherence and distress was found in a

study of child and maternal adjustment to cystic fibrosis and insulin-dependent diabetes mellitus (Mullins, Chaney, Hartman, & Olson, 1995). The importance of individuals being informed of their expected illness course was further highlighted in a study of worry of recurrence in long term testicular cancer (Skaali et al., 2009) which indicated an association between level of education and worry of recurrence. As a consequence of study outcomes, the authors stressed the importance of “individually adjusted and repeated information about recurrence for each patient” (Skaali et al., 2009, p. 586). Overall, while studies of how coherence beliefs impact worry of recurrence are scarce, it appears that limited understanding of illness impacts worries of recurrence and overall psychological wellbeing.

*Control and cure beliefs.* Research has indicated the importance of perception of control in response to stressful events, on both the physical and psychological health of individuals (Shapiro et al., 2001). Given that women often experience a loss of control following a diagnosis of breast cancer (Andersen, Kiecolt-Glaser, & Glaser, 1994), it is likely that this may also impact their worries of cancer recurrence post treatment. Studies have indicated that a positive sense of control was associated with better adjustment in breast cancer survivors at 6 months following the end of treatment (Ell, Nishimoto, Movay, Mantell, & Hamovitch, 1989). Similar findings were uncovered in a study of gynaecological cancer survivors which found that perceptions of greater personal and treatment control, as well as fewer disease consequences contributed to lower levels of cancer worry (Gould, Brown, & Bramwell, 2010).

*Breast cancer imagery and worry of cancer recurrence.* Few studies have examined the association between women’s mental imagery of breast cancer and worries of recurrence, despite research indicating the potential impact of mental imagery on illness worry and health related behaviours (Cameron, 2008; Stacy, Ames, & Knowlton, 2004a; Stacy, Pearce, Zogg, Unger, & Dent, 2004b). The importance of understanding mental imagery has been

highlighted in research indicating the impact of mental imagery on health worry, protective behaviours and adjustment (Broadbent, Ellis, Gamble, & Petrie, 2006; Cameron, 2008). The implications of further research in this area, include the ability to modify an individual's mental image and as a consequence influence their behaviour, psychological wellbeing and health outcomes (Cameron & Chan, 2008).

One of the only studies to investigate mental imagery in breast cancer survivors was by Harrow and colleagues (2008) which examined the meaning, content, and consequences of mental images in women who had completed treatment for primary breast cancer. Outcomes suggested that women's cancer imagery was influenced by mammograms, and metaphors and drawings used by medical professionals in their communication with them. The majority of participants, 14 out of 15 women, had a mental image of their cancer which reflected their beliefs surrounding the appearance, character and the danger posed by their illness. This included specific details of the shape, colour, texture, consistency and size of the cancer. In addition mental images reflected properties of the cancer including the 'behaviour' and intent of the disease, often the cancer was depicted as 'creature-like', 'substance-like' or a combination of both. Women who perceived their cancer as 'creature like' appeared to convey the idea of the cancer being parasitic while imagery contents that included a more lifeless entity suggested that the cancer was perceived as less dangerous. Mental images women presented were often described as being red, white, grey or black. It appeared that colour also conveyed the level of danger the cancer presented, with mental images of a white or grey substance representing a more benign cancer and red or black cancer images reflecting the cancer as being more threatening and dangerous. In some cases, women's cancer imagery was reflective of perceptions of doubt as to whether their cancer could be removed completely and successfully. Overall, the outcomes of the investigation indicated that women's cancer imagery impacted on their cancer concerns and worries of recurrence.

*Summary of findings.* Thus far, it appears that studies of illness representation in breast cancer survivors have only concentrated on particular domains of the Self-Regulation Model, while studies investigating the association between all domains of the model and women's worry of recurrence specifically is scarce. It was also noted that few studies evaluated the roles of age, trait anxiety, and treatment type and whether these factors might account for the observed associations between illness representations and worry about cancer recurrence. In relation to trait anxiety, a study of breast cancer survivors found that trait anxiety was linked to more constant activation of illness representations influencing cancer worry, greater somatic awareness and coping efforts (Cameron & Chan, 2008). Similarly, Watson and Clark (1984) highlighted the link between higher levels of trait anxiety with worry and fear, due to heightened threat perceptions in response to external and internal cues.

The current study will bridge the gap in research by exploring the impact of all dimensions of the Common Sense Model on women's worries of recurrence and will take into account age, trait anxiety and the type of breast cancer treatment women received.

## **Section 6: Coping Responses Following Treatment for Primary Breast Cancer**

While the association between coping responses and psychological adjustment post treatment in breast cancer survivors has been well researched, studies investigating how women cope specifically with their worries about cancer recurrence are scarce. One of the gaps in the current research includes the lack of a psychometric measure for assessing women's coping strategies aimed at alleviating their worries of recurrence. As such one of the aims of the current study is the development and validation of a coping with worries of cancer recurrence measure. This will be used to examine the impact of women's coping strategies on levels of recurrence worry both concurrently and over the short term. Given the impact of women's worries of recurrence on their psychological wellbeing, a better understanding of how coping influences recurrence worries may be fundamental for the

development of interventions aimed at reducing cancer worry and improving psychological adjustment. As research pertaining to coping with worries of recurrence is minimal, the following review focuses on the impact of coping on psychological wellbeing in breast cancer survivors and includes some of few studies examining the relationship between coping and recurrence worry.

### ***The impact of emotional regulation strategies on psychological adjustment***

The ‘Coping with Worry of Cancer Recurrence Measure’ designed in the current study will implement the emotional regulation strategies within the context of the Common Sense Model outlined by Cameron And Jago (2008) to examine the relationship between women’s coping and levels of worry of recurrence. These include strategies of: problem solving, attentional deployment (avoidance and distraction); cognitive change (eg. optimistic thinking, spirituality); emotional modulation (expression, suppression, humour and substances coping) and proactive behaviours (eg. healthy behaviours). While avoidance coping can be assessed using the established Impact of Events Scale Revised (IES-R) (Weiss, 2007) measure which can be tailored to assess the use of avoidance to cope with worry of recurrence, the need for development of the new measure was prompted by the lack of measures targeting other emotional regulation strategies aimed at alleviating women’s worry of recurrence. In particular, the COPE measure (Carver, Scheier, & Weintraub, 1989) was deemed unsuitable as a whole to assess women’s worry of recurrence specifically given its design to assess coping for a variety of general stressors. Furthermore, this measure does not target specific coping domains of interest including suppression of emotions, optimistic thinking and distraction. However, some items included in the new ‘Coping with Worry of Recurrence Measure’ pertaining to spiritual coping, expression and humour were adapted for use from the COPE measure (Carver et al., 1989).

Several patterns were uncovered in literature pertaining to the relationship between emotional regulation and adjustment following treatment for breast cancer. Overall, coping strategies of problem focused coping, hopefulness and optimism (Epping-Jordan et al., 1999), expression (Stanton et al., 2000) and humour (Carver et al., 1993) have been shown to be significantly associated with better psychological adjustment following treatment. On the other hand, poor adjustment a greater psychological distress has been associated with emotional suppression (Classen, Koopman, Angell, & Spiegel, 1996), anxious pre-occupation (Schnoll, Harlow, Stolbach, & Brandt, 1998), avoidance based coping (McCaul et al., 1999) and social withdrawal (Holland & Holahan, 2003).

*Problem Solving.* Active engagement with difficulties, including the use of problem solving strategies have almost consistently been demonstrated to produce better adjustment and less distress in breast cancer survivors in comparison to avoidance focused coping (Stanton et al., 2000). Problem solving may be conceptualised as “defining the problem, generating alternative solutions, weighing and choosing among alternatives, altering environmental stressors, changing goal expectations, finding alternative channels of gratification, and learning new skills and behaviours” (Fredette, 1995, p. 37). Studies evaluating the impact of problem solving strategies on wellbeing in breast cancer survivors have utilised measures that include the Revised Ways of Coping Measure (Folkman & Lazarus, 1985) and the Coping Responses Inventory (Moos, 1988). These measures were noted to tap into the conceptualisations of problem focused coping as defined by Fredette (Fredette, 1995).

A study of 56 women up to 26 months post diagnosis for breast cancer found that planful problem solving and positive reappraisal were positively associated with adjustment (Holland & Holahan, 2003). Similar findings were reported in a review by Royak-Schaler (Royak-Schaler, 1991) who indicated positive adjustment and quality of life in women who

were actively involved in during their diagnosis and treatment through use of problem solving strategies, emotional expression and lifestyle changes.

A study of worry of worry of recurrence in breast cancer survivors found an opposite association, with moderate and high levels of worry of recurrence related to greater use of problem solving strategies (Mehnert et al., 2009). The authors hypothesized that this was due to women who used more problem solving coping being more 'future orientated', thus fearing the costs of recurrence more keenly than their counterparts. A further theory proposed by the researchers, were that women with higher recurrence worry may be more likely to adopt problem solving as a coping strategy as opposed to those experiencing less recurrence worry. Given outcomes of this research, it is expected that higher use of problem solving strategies in the current study will be associated with higher levels of worry of recurrence.

*Avoidance.* While research on the benefits of avoidant coping is mixed, the majority of studies appear to suggest an association between avoidance based coping and poor adjustment, including increased levels of distress and poor quality of life in breast cancer survivors (Hack & Degner, 2004; Holland & Holahan, 2003; McCaul et al., 1999).

A study of 55 women, within six months post breast cancer diagnosis found that cognitive avoidance was associated with significantly worse psychological adjustment including higher levels of anxiety and negative mood (Hack & Degner, 2004). Similar findings were reported by Stanton (2000) indicating associations between avoidance coping and distress in breast cancer survivors following treatment and at follow up 3 months later. This was consistent with an earlier investigation indicating avoidance focused coping as a strong predictor of low vigour (Stanton & Snider, 1993).

In relation to worries of recurrence, avoidance based coping was found to be a predictor of reductions in worry of recurrence at 3 months, but increases in worry of recurrence at 1 year (Stanton, Danoff-Burg, & Huggins, 2002). Views on the benefit of

avoidance strategies are conflicted, with Glanz and Lerman (1992) proposing that during stages of active treatment, avoidance strategies are adaptive due to women having little control over their care, including treatment side effects. However, Stanton and Snider (1993) argue that avoidance requires effort in itself while hindering the opportunity for positive decision making, thereby hindering positive adjustment. Overall, it appears likely while avoidance strategies might be useful over the short term, Stanton and Snider's (1993) theory explains the negative impact of avoidance coping on worries of recurrence over the longer term. A similar relationship between avoidance strategies and worry of recurrence is expected in the current investigation.

*Distraction.* Few studies have examined the association between distraction coping and wellbeing in breast cancer survivors. Yet it has been identified as a frequently used coping strategy for breast cancer survivors following treatment (Cameron et al., 2005; Jingzhi & Lambert, 2007) including as a coping mechanism for worries of recurrence (Leventhal et al., 2003). Upon examination of the literature, distraction appears to be conceptualised as a specific type of avoidance coping, with existing investigations yielding mixed findings in relation to the association between distraction and psychological wellbeing.

Hack and Degner (1999) who investigated three distinct clusters (low avoidance, moderate avoidance and high avoidance) of women with breast cancer, between 1.5 and 6 months post diagnosis, found that women who were low on avoidance, including distraction coping had significantly better psychological adjustment than women in the remaining clusters. A further investigation found similar associations between distraction coping and levels of distress in breast cancer survivors post-operatively and at 3 months follow up (Carver et al., 1993). However, in contrast to these findings, Lauver and colleagues (2007) found that survivors of breast and gynaecological cancers up to 4 months post treatment, rated distraction coping highly for stressors including uncertainty about treatment, difficulties

dealing with mortality and physical concerns. While findings appear to be mixed, it is expected that distraction will be negatively associated with women's worry of recurrence in the current study.

*Cognitive reappraisal and optimistic thinking.* Cognitive reappraisal in relation to illness may be defined as altering one's perceptions about disease and one's ability to cope with it. Studies of cognitive reappraisal appear to be focused on positive reappraisal which has been highlighted in breast cancer literature as having both psychological and physical benefits for women. A study of women with early stage breast cancer found that positive reappraisal was a predictor of positive mood and perceived health at three and 12 months post breast cancer treatment (Schnoll et al., 1998). In relation to worry of recurrence, it has been suggested that breast cancer survivors who experience higher levels of worry of recurrence use positive reappraisal to a greater degree than women with less recurrence worry (Hilton, 1989). However, positive reappraisal has also been associated with reductions in worry of recurrence, in a further investigation of distress in breast cancer survivors up to 6 years post diagnosis (Mast, 1998). These findings may be interpreted as women with greater worry of recurrence turning to positive reappraisal to cope with their distress, and experiencing the benefits of reductions in worry of cancer recurrence over time.

While some overlap may exist between constructs of cognitive reappraisal and optimistic thinking, cognitive reappraisal may be considered as a more "effortful process" (Sears, Stanton, & Danoff-Burg, 2003, p. 489). Optimistic thinking (Carver et al., 1993) or hopefulness (Stanton et al., 2002) has been associated with lower distress in women with breast cancer as well as those in remission. This has been attributed to women who are hopeful being generally better at realizing their goals, finding means of attaining goals and eliciting the motivation required to do so (Snyder, Harris, & Anderson, 1991). These findings were supported in research indicating associations between optimistic thinking and greater

emotional expression, with hope predicting better psychological adjustment in breast cancer survivors following treatment and at follow up 3 months later (Stanton et al., 2000).

Optimistic thinking has also been identified as a common coping strategy for cancer recurrence worry in women following breast cancer (Leventhal et al., 2003). A study by Stanton and colleagues (2002) found that optimistic thinking in highly hopeful women was associated with lower levels of worry of recurrence. The authors attributed this relationship to these women having more positive treatment expectancies and more confidence in their own ability to contribute to their recovery. Given research indicating positive outcomes for women using optimistic thinking strategies, similar patterns of association are expected in the current study between optimistic thinking and worry of recurrence.

*Spirituality.* The efficacy of spiritual coping on wellbeing during periods of stress has been attributed to its ability to provide hope, a sense of control, belonging and comfort (Tix & Frazier, 1998). For women with breast cancer, spiritual coping includes prayer, meditation, religious aspects, or turning to god (Fredette, 1995). Research indicates that spiritual coping is commonly used, with female cancer survivors describing it as one of the most beneficial coping strategies following treatment (Cameron et al., 2005). According to Johnson and Spilka (1991) approximately 85.0% of women turn to religion as a means of coping with breast cancer.

Despite the frequency of its use, research pertaining to the influence of religious coping on psychological wellbeing appears to be minimal, with existing research indicating mixed associations between spiritual coping and wellbeing. An investigation by Hebert and colleagues (2009) of breast cancer survivors explored the relationship between positive and negative religious coping on physical and mental wellbeing, depression and life satisfaction. A total of 76.0% of the cohort reported using religious coping a moderate amount or a lot of the time. Positive religious coping was viewed as positive appraisals of the relationship with

God, while negative religious coping was viewed as a conflicted relationship, characterised by negative appraisals including feelings of abandonment or punishment. Outcomes of the study indicated no relationship between positive coping and wellbeing while negative religious coping was associated with poorer psychological wellbeing, including depression.

However in relation to coping with worries of recurrence, Stanton and colleagues (2002) found that for women low on hope, high turning to religion was associated with lower levels of worry of recurrence and more positive adjustment at one year post diagnosis. In contrast, for women who were high on hope, turning to religion was correlated with poorer adjustment over time. The authors propose that for women low on hope, spirituality allows them to experience a sense of control and comfort while for women high on hope, turning to religion may represent a sense of low control as well as avoidance, factors that have been associated with greater distress in breast cancer survivors. In contrast to these findings, other findings suggested that coping through religion was associated with higher levels of worry of recurrence in breast cancer survivors an average of 47 months post diagnosis (Mehnert et al., 2009). However, it is important to point out that the influence of hope as a mediating variable was not assessed in this investigation.

Despite, outcomes pertaining to the relationship between spiritual coping and worry of recurrence being mixed, it is anticipated that a positive relation will be uncovered between these variables in the current study.

*Expression.* The positive benefits of expressive coping have been attributed to allowing the individual to clarify goals and to attend to their key concerns (Frijda, 1994), to the garnering of positive social response (Stanton et al., 2000) and to the process of habituation whereby increased expression results in decreases in negative emotion and arousal (Foa & Kozak, 1986). While the positive impacts of expressive coping on the wellbeing of breast cancer has been illustrated in empirical studies of support group

interventions (Goodwin et al., 2001), the literature pertaining to the impact of emotional expression on psychological adjustment is mixed. For example, Compas and Colleagues (1999) found that emotional expression was significantly associated with poor psychological adjustment in breast cancer survivors, while Classen and colleagues (1996) indicated that emotional suppression was detrimental to adjustment.

Hack and Degner (2004) propose that discrepancies may be due to conceptualisations of ‘emotional expression’, a view that has also been suggested by Stanton (2002) who argues that items assessing emotional expression are sometimes “distress laden” and contain “self-deprecatory content” (Stanton et al., 2000, p. 876). A study investigated the impact of two distinct coping mechanisms of emotional expression and emotional processing, mechanisms which have often been conceptualised as being the same, on the wellbeing of breast cancer survivors (Stanton et al., 2002). The investigation found that greater emotional expression relating to cancer was associated with better physical health, vigour, less distress and fewer medical visits, while emotional processing was correlated with greater distress over time. The authors surmised that cognitive processing may reflect cognitive rumination, explaining the exacerbation of distress in survivors. It can be argued that emotional expression is also a reflection of obtaining social support. In relation to social support, it has been highlighted to have a crucial role in women’s psychological adjustment following a diagnosis of breast cancer (Moyer & Salovey, 1996; Spiegel, 1997). As emotional expression as opposed to emotional processing is being evaluated in the current study, it is expected that greater use of emotional expression will be associated with lower levels of worry of recurrence.

*Suppression.* The suppression of negative emotions has been associated with poorer psychological outcomes in women with breast cancer (Watson et al., 1991). A study of suppression coping in breast cancer patients found that suppression was negatively related to the reporting of socially embarrassing chemotherapy symptoms and with coping appraisal,

and positively associated with experiencing symptoms consistent with poorer immune functioning (Schlatter & Cameron, 2010). The authors suggested that “emotional suppression influences self-regulation efforts to manage cancer experiences in ways that undermine psychological and physiological processes involved in adjustment and cancer control” (Schlatter & Cameron, 2010, p. 15).

Application of these findings to the current study suggests that women who use suppression strategies to a greater degree may be more unlikely to report and seek assistance for embarrassing symptoms. It is plausible that experiences of greater cardiovascular symptoms compounded by unresolved embarrassing symptomology, may exacerbate arousal and perceptions of symptoms as indicators of cancer recurrence. Overall, it is expected that unresolved negative emotions combined with symptom experiences will manifest as greater worry of recurrence in women who use suppression coping to a greater extent.

*Humour.* The benefits of using humour to cope with a cancer diagnosis, treatment and prognosis has been commonly reported by cancer patients and survivors (Johnson, 1998). A study of nine women diagnosed with breast cancer identified humour as an important coping strategy for women, one that was related to spirituality and beliefs of the meaning or purpose of life (Johnson, 2002). Women in the study reported benefits of humour including as a means of relaxing, creating cohesiveness, developing comfort within a support group context and as a means of maintaining hope. These findings were consistent with a literature review of humour as a coping mechanism in cancer patients which found a positive association between humour and levels of comfort, wellbeing and relaxation (Christie & Moore, 2005). The benefits of humour coping was also demonstrated in an investigation of 59 breast cancer survivors which found that higher use of humour was associated with lower distress post-surgery and at 6 month follow up (Carver et al., 1993). I noted that research pertaining to the impact of humour on worries of recurrence in breast cancer survivors was virtually non-

existent. However, given studies indicating positive psychological outcomes in breast cancer survivors using humour coping, a similar relationship is anticipated in relation to women's worry of recurrence in the current study.

*Healthy Living and Substances Coping.* Studies pertaining to the relationship between health behaviour focused coping, or the use of alcohol and drugs to cope, with worry of recurrence in breast cancer survivors is scarce. Costanzo and colleagues (2011) found significant improvements in health practices, including changes in diet and increases in exercise, as well as reductions in alcohol and cigarette use, in breast cancer survivors following treatment. This appeared to reflect coping efforts directed at alleviating worries of recurrence. A further study found an association between age and health behaviours, with younger breast cancer survivors reporting more health related changes to their diet and exercise regime to avoid cancer recurrence (Thewes, Meiser, & Hickie, 2001). The use of health related coping also appears to be related to time since diagnosis, with short term cancer survivors of colorectal cancer reporting higher levels of exercise to manage worries of recurrence, than long term survivors up to 14 years post treatment (Cameron & Leventhal, 2003). Substance use specifically, has been reported as one of the least frequently used coping strategies for stressors, in women with breast and gynaecological cancers post treatment (Cameron et al., 2005).

## **Section 7: Summary of the Literature Review**

The literature to date highlights the prevalence and enduring quality of worry of recurrence for breast cancer survivors and its detrimental effects on women's wellbeing and adjustment post treatment. Of particular note were the various factors likely to predict women's worry of recurrence, including age, treatment type, levels of trait anxiety, time since diagnosis, mental representations of breast cancer and coping strategies. Overall, these factors highlight the potential differences that may exist among breast cancer survivors in terms of

the extent to which they experience worry of recurrence and adapt to it. An understanding of these differences may be crucial for early identification and intervention in women at high risk of psychological difficulties post treatment.

Thus far, it is evident that existing research has predominantly focused on the impact of age, treatment type, time since diagnosis and mental representations on general psychological adjustment post treatment, however, few studies have examined the relationship between these factors and levels of worry of recurrence in breast cancer survivors. Furthermore, while existing studies have suggested that higher levels of recurrence worry is correlated with younger age, increased levels of anxiety, depression, post traumatic symptomology and poorer quality of life, research pertaining to the associations between worry of recurrence and adjuvant treatment and illness perceptions is severely limited.

With regards to the imagery domain of illness representations, quantitative evaluation of women's breast cancer imagery on levels of worry of recurrence is non-existent. As indicated by research, illness representations including mental imagery should guide emotional regulation; as such it is expected that this will influence women's worry of recurrence over time. It was also noted that studies to date have not examined the relationship between all domains of illness representations as described by the Self-Regulation Model, on levels of worry of recurrence in breast cancer survivors. In particular, the influence of age, treatment, trait anxiety and time since diagnosis were often not included in studies of the relationship between illness representation domains and worry of recurrence, despite research citing the possible impact of these variables on cancer worry. It is anticipated that age, trait anxiety, adjuvant treatment effects and time since diagnosis will influence women's illness representations of consequences, identity or control beliefs in ways that may impact their worry of recurrence.

With regards to treatment it should be pointed out that there is a dearth of research pertaining to the associations between adjuvant treatment and worries of recurrence specifically, as research thus far appears limited to the relationship between treatment and general quality of life and psychological adjustment in breast cancer survivors. Overall, the current research aims to attend to these gaps in the literature through a more in depth exploration of the impact of age, treatment, trait anxiety and illness representations on women's worries of recurrence.

Finally, there is a significant gap in the current literature relating to women's emotional regulation of recurrence worry, post breast cancer treatment. In particular, there are no psychometric measures available to assess women's coping specifically directed at their worry of recurrence. Furthermore, research thus far has tended to focus on the impact of coping with general stressors on adjustment, including women's psychological wellbeing post treatment. As a consequence, one of the goals of the current research is the development and validation of a coping with worry of recurrence measure using the emotional regulation strategies delineated in the extended Common Sense Model of Self Regulation (Cameron & Jago, 2008). This will be used to attend to gaps in current research relating to the association between women's coping directed at alleviating recurrence worry, on actual levels of worry of recurrence both concurrently, and over the short term. It is anticipated that a greater understanding of how coping influences worry of recurrence, will benefit the development of interventions targeted at reducing worries of recurrence and improving psychological wellbeing in women post breast cancer surgery.

## **Section 8: Study Outline and Hypotheses**

### ***Study outline***

The current research consists of two parts; a pilot study and main study, both of which are questionnaire based. Women five years post breast cancer treatment were recruited for the

pilot study, as opposed to three years post treatment for the main study due to the limited pool of participants available.

The purpose of the pilot study was the validation of the new 'Coping with Worry of Cancer Recurrence' measure. The pilot study consisted of 71 women, who were recruited via the New Zealand cancer Registry and through breast cancer support groups. Women were expected to complete either a hard copy of the study questionnaire or an online version containing the new 'Coping with Worry of Recurrence Measure' and measures used to determine the convergent and discriminant validity of the measure. This included measures of worry of cancer recurrence (McCaul's Brief Worry Measure), anxiety and depression (Hospital Anxiety and Depression Scale) and post traumatic symptoms (Impact of Events Scale Revised). The Worry of Recurrence Measure was amended following the pilot study and used in the main investigation to examine associations between women's emotional regulation strategies and levels of worry of recurrence.

The main study was a longitudinal investigation consisting of two hard copy questionnaires completed a month apart. In total, 143 women who were three years post breast cancer diagnosis were recruited for the study via the New Zealand Cancer Registry. The aims of the investigation was two-fold: (1) to examine the relationship between worry of cancer recurrence and variables of age, trait anxiety, adjuvant treatment, time since diagnosis, anxiety and depression (Hospital Anxiety and Depression Scale), posttraumatic symptoms (Revised Impact of Events Scale), quality of life (Short Form 36 Quality of Life Measure) and women's illness representations (Illness Perceptions Questionnaire Revised) including imagery groups (adapted from Assessment of Illness Representations Revised); and (2) to evaluate whether emotional regulation strategies (Coping with Worry of Cancer Recurrence measure and the avoidance subscale of the Impact of Events Scale Revised) predicted women's worries of cancer recurrence both concurrently and over a month. This time frame

was chosen as the current research was focused on understanding the short term dynamics between emotional regulation strategies and worry. Given that self regulation dynamics change overtime, it was expected that the extent to which concurrent coping predicts longer term outcomes would be weak.

These investigations also included age, cancer treatment, trait anxiety and time since diagnosis as covariates to examine the influence of these variables on associations between worry of recurrence and relevant psychological constructs.

### ***Research hypotheses***

The purpose of the current research was to explore five main hypotheses that were deemed to enhance our understanding of the relationship between worry of cancer recurrence and psychological wellbeing; and the link between women's mental conceptualisation of breast cancer and coping strategies on levels of cancer worry.

*Hypothesis 1.* Following principal components analyses, items pertaining to each subscale of the 'Coping with Worry of Recurrence Measure' will rotate onto the relevant subscale as predicted. Convergent validity will be confirmed by the following patterns of association: a negative correlation between strategies of expression and suppression coping; a positive correlation between spirituality and expression; a negative correlation between spirituality and suppression; and a negative relationship between optimistic thinking and anxiety. Discriminant validity will be suggested by a lack of correlation between theoretically unrelated subscales or measures, for example between spiritual coping and healthy living, or spiritual coping and distraction.

*Hypothesis 2.* Younger age, shorter time since diagnosis, and use of chemotherapy and hormonal treatment will be associated with higher levels of worry of recurrence.

*Hypothesis 3.* Higher levels of worry of recurrence will be associated with greater anxiety, depression and post traumatic symptoms. In relation to quality of life, higher levels

of worry of recurrence will be associated with poorer functioning on all domains of quality of life including physical functioning, physical and emotional roles, social functioning, pain, vitality, general health and mental health.

*Hypothesis 4.* Higher scores on the acute/chronic timeline, consequences, cyclical timeline, emotional representations and identity domains of illness representations will be associated with higher levels of worry of recurrence. On the other hand, higher scores on the personal control, treatment control and coherence domains will be related to lower levels of worry of recurrence. In relation to imagery groups of breast cancer, images of cancer that indicate an entity that has intent or is life-like will be related to high levels of worry of recurrence as opposed to images of an inanimate object or lump.

*Hypothesis 5.* Greater use of problem solving, avoidance, distraction, suppression, and substances coping will be associated with higher levels of worry of recurrence. However, optimistic thinking, spiritual coping, expression, humour and healthy living and will be related to lower levels of worry of recurrence. Similar patterns are expected for the relationship between coping and levels of worry of recurrence concurrently and over the period of a month.

## CHAPTER II: PILOT METHODS

### Study Design

This pilot study investigated the psychometric qualities of a newly developed measure titled ‘Coping with Worry of Cancer Recurrence’. This scale was designed to assess the coping strategies outlined in the Common Sense Model of Self-Regulation (CSM). Breast cancer survivors were recruited for the purposes of assessing the psychometric qualities of the scale and these participants were not part of the larger study. This study implemented a cross-sectional design. Psychometric assessments included correlational, reliability and principal components analyses to assess the internal consistency as well as the convergent validity and discriminant validity of the coping measure with the following constructs/measures: McCaul’s Brief Worry Measure, Hospital Anxiety and Depression Scale and the Impact of Event Scale Revised.

### Participants

The participants of the study consisted of 71 female breast cancer survivors who had completed treatment for primary breast cancer within the past five years. Participants were recruited from the New Zealand Cancer Registry (NZCR) and breast cancer support groups in the Auckland region using the following inclusion criteria: (a) Ages of 18 years and over; (b) Treatment for primary breast cancer within the past five years; (c) No recurrence of the cancer following treatment; (d) No current treatment for major depression or other psychological disorders; and (e) ability to read and understand English. All participants were invited to participate in the study through invitations sent out by mail. They were given the option to either complete a hard copy of the questionnaire or complete it online via the Survey Monkey website. The Table 2-1 shows a summary of the demographic characteristics of the participants:

Table 2-1. *Demographic Characteristics of the Sample*

Variable	Total	Percentage
<i>Ethnicity (N = 71)</i>		
NZ Maori	6	8.5
NZ European / Pakeha	59	83.1
NZ Chinese	1	1.4
Asian	2	2.8
Indian	1	1.4
Cook Island Maori	1	1.4
Other	1	1.4
<i>Women with Children (N = 70)</i>		
Yes	62	88.6
No	8	11.4
<i>Marital Status (N = 60)</i>		
Married	52	73.2
Single	5	7.0
Living With Partner	3	4.2
Divorced	6	8.5
Widowed	5	7.0
<i>Income Level (N = 67)</i>		
Less than \$20,000	8	11.3
\$20,001 - \$40,000	11	15.5
\$40,001 - \$60,000	16	22.5
\$60,001 - \$80,000	7	9.9
\$80,001 - \$100,000	8	11.3
\$101,000 or above	17	23.9
<i>Education Level (N = 60)</i>		
Year 9	3	4.5
Year 10	6	9.0
NCEA Level 1	19	28.4
NCEA Level 2	0	0
NCEA Level 3	4	6.0
Trade Certificate	1	1.5

National Certificate or Diploma	21	31.3
Bachelor's Degree	12	17.9
Masters Degree/ Doctorate or PhD	1	1.5

Note. *N* = Number of valid cases; 'Others' in ethnicity includes a participant of South African European Descent

## **Coping With Worry of Cancer Recurrence Measure**

### *Items development and structure*

The Worry of Cancer Recurrence Measure (see Appendix A1) was designed using the problem focused and emotion focused strategies outlined in the CSM. This model highlights the influence of health threats in the activation of both the cognitive and emotional components of the model (Cameron & Jago, 2008 ).

The emotional coping strategies outlined by James Gross (2007) and which comprise the CSM provided the basis for the creation of the coping measure designed in the current study. These strategies include the diverting of attention either away from the illness threat or the focusing of attention on the threat; the use of pro-active behaviours aimed at threat reduction; cognitive change or re-appraisal; and response modulation which refers to the individual's attempts at modifying emotions and their expression, including suppression and expression behaviours (Cameron & Jago, 2008 ). Items were also chosen based on literature findings highlighting the coping strategies utilised by women post cancer treatment to manage their recurrence worries.

The coping categories isolated through the CSM and highlighted via the literature were as follows: 'problem solving', 'distraction', 'optimistic thinking', 'spirituality' 'expression', 'suppression' and 'healthy living.' Items devised for the coping measure were specifically phrased and generated to assess these coping strategies. Additional items relating to coping strategies reported by breast cancer survivors of; I try to laugh it off, I use alcohol or drugs to help me cope, I comfort myself by eating food and I visit my doctor were also

included in the measure for further exploration. Responses were made on a four point scale of anchors of 1 (*Almost Never*), 2 (*sometimes*), 3 (*often*), and 4 (*almost always*).

Prior to completing the questionnaire, women were prompted to answer a dichotomous question with *Yes* or *No* responses: “Do you ever experience concern or worry about your cancer recurring or coming back even if it’s just a little bit?” Only women who indicated that they experienced cancer worries were instructed to complete the subsequent questionnaire items presented in Table 2-2. The list of questionnaire items was preceded by the stem, ‘when I feel worried about the cancer returning.....’ This statement was specifically phrased to access the coping strategies women used to manage their worries of cancer recurrence.

Table 2-2. *List of initial items for the Coping with Worries of Cancer Recurrence Scale*

Items
<i>Problem Solving</i>
I think through the reasons why the cancer may or may not come back.
I think through what might happen if it does come back
I check myself for symptoms or signs that the cancer has returned
I focus on coming up with a strategy of what to do
<i>Distraction</i>
I distract myself by doing something else (work or other activities)
I try to ignore or push these thoughts out of my mind
<i>Optimistic Thinking</i>
I focus on the positive aspects of my experience with cancer
I reassure myself that I’m fine, healthy and strong
I tell myself that I can handle it if the cancer comes back
<i>Spirituality</i>
I pray
I ask others to pray for me
I go to my place of worship (church, temple, etc.)
I trust in God to help me cope
I focus on the spiritual aspects of my experience
I go to places where I can connect with my spirituality

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*Expression*

- I talk to a friend, partner or family member about it
- I write about it
- I let others know how I feel
- I seek physical affection such as hugs from my family, partner or friends
- I ask for advice from my family, partner or friends
- I seek out sympathy and understanding from others

*Suppression*

- I keep it to myself
- I hide those feelings from others
- I smother my feelings

*Healthy Living*

- I try to eat a healthier diet
- I try to include exercise in my daily routine
- I do things that help me relax, such as deep breathing, yoga, etc.
- I look for more information about cancer or cancer recurrence

*Additional Items*

- I try to laugh it off
  - I use alcohol or drugs to help me cope
  - I comfort myself by eating food
  - I visit my doctor
- 

***Pilot testing***

The Coping with Worry of Recurrence Measure was evaluated for relevance to the construct being studied, readability and applicability by nine judges (clinical psychology postgraduate students, health psychology postgraduate students and a health psychologist, all of whom had expertise in emotional regulation and coping in response to health threats). The judges confirmed that each of the items comprising the scale had satisfactory face validity. To determine content validity, judges were instructed to evaluate which items corresponded to each coping category. These were successfully identified as belonging to the ‘problem focused’, ‘distraction’, ‘optimistic thinking’, ‘spirituality’, ‘expression’, ‘suppression’ and ‘healthy living’ subscales. The measure takes approximately five minutes to complete and

minor revisions pertaining to the wording of items and the addition and deletion of items were done to improve readability, clarity and the overall comprehensiveness of the scale.

## **Measures**

The pilot questionnaire included the ‘Coping with Worry of Cancer Recurrence Scale’, measures of demographics, cancer treatment, anxiety and depression, impacts of breast cancer and cancer worry.

### ***Demographics***

The following demographic characteristics were assessed using a demographic information sheet (see Appendix A3): (1) age in years, (2) ethnicity (i.e. NZ Maori, NZ European / Pakeha, Pasifika, Asian, Indian or other (please specify)), (3) occupation, (4) highest level of education completed (i.e., year 9, year 10, NCEA level 1, NCEA level 2, NCEA level 3, trade certificate, national certificate or diploma, bachelor’s degree, master’s degree or PHD, or other (please specify)), (5) marital status (ie. married, single, living with partner, divorced, widowed or separated), (6) whether or not the respondent has children and if so how many and (7) current socioeconomic status (i.e., less than \$20,000 per year, \$20,001 - \$40,000 per year, \$40,001 - \$60,000 per year, \$60,001 - \$80,000 per year, \$80,001 - \$100,000 per year, or \$101,000 or above).

### ***Cancer treatment***

Four questions were asked to gather information about cancer treatment: (1) how much time had lapsed since cancer diagnosis in months (2) the main type of cancer treatment received (ie. radiotherapy, chemotherapy, surgery, hormonal therapy, or other (please specify)), (3) other forms of treatment received (ie. radiotherapy, chemotherapy, surgery, hormonal therapy, or other (please specify)), and (4) whether or not relapse had occurred.

### ***Current mental health***

Participants were asked if they were currently undergoing treatment for depression or any other psychiatric disorder and if so they were prompted to elaborate on what condition they were currently receiving treatment for.

### ***Worry about Cancer Recurrence***

The McCaul's Brief Worry Measure (see Appendix A5) (McCaul, Branstetter, O'Donnell, Jacobson, & Quinlan, 1998) was adapted to assess the extent of women's worries of cancer recurrence. The items of the questionnaire were as follows: (1) How worried are you about having a recurrence of breast cancer?; (2) How concerned are you about having a recurrence of breast cancer?; (3) How much does thinking about a recurrence of breast cancer bother you?; and (4) To what extent are you confident that your body can control your cancer and stop it from spreading? The responses anchors for each of the questions ranged from 0 = *not at all* to 6 = *extremely*. A study by Cameron (2008) revealed good internal consistency for the measure ( $\alpha = .87$ ) and a test-retest reliability of  $\alpha = .66$ .

### ***Hospital Anxiety and Depression Scale (HADS)***

The Hospital Anxiety and Depression Scale (see Appendix A6) (Zigmond & Snaith, 1983) is a widely used and reliable measure of anxiety and depression in cancer patients (Osborne, Elsworth, Sprangers, Oort, & Hopper, 2004).

The HADS is a 14 item measure consisting of two independent subscales for anxiety and depression which are interpreted separately using the following ranges: normal (0-7), mild (8-10), moderate (11-14) and severe (15-21). Each of the items comprising the scale is answered on a four point (0-3) response category with possible scores ranging from 0 to 21 for anxiety and 0 to 21 for depression. A score of 0 to 7 for either subscale is interpreted as falling within the normal range with scores of 8-10 being suggestive of a mood disorder. On

the other hand, scores of 11 or higher on either subscale indicates 'caseness' or the presence of a mood disorder.

It has been demonstrated to have good internal consistency and test-retest reliability for both breast cancer patients and those without breast cancer (Herrmann, 1997). Research has determined a Cronbach's alpha of 0.78-0.93 for the HADS suggesting satisfactory to high internal consistency.

### ***Impact of Event Scale Revised (IES-R)***

The Impact of Events scale Revised (see Appendix A7) (Weiss & Marmar, 1997) was used to evaluate the degree of distress a patient feels in response to the possibility of the cancer returning and also the extent to which they use avoidance strategies, and their levels of rumination and hyperarousal. The IES-R comprises of 22 questions and three subscales; intrusion, avoidance and hyperarousal. Five items relating to hyperarousal were added to the original Horowitz (IES) by Weiss and Marmar (1997). The IES (Impact of Event Scale) was an early self-report scale designed to measure current subjective distress in relation to a specific stressor (Horowitz, Wilner, & Alvarez, 1979) and is widely used to assess post-traumatic stress.

Respondents are asked to report on the degree of distress of each symptom (eg. any reminder brought back feelings about it) during the past seven days using the following response anchors: 0 = *Not at all*, 1 = *A little bit*, 2 = *Moderately*, 3 = *Quite a bit*, and 4 = *Extremely*. The extent to which an individual experiences particular symptomology is ascertained via an examination of the mean scores obtained for each subscale. Weiss and Marmar (1997) reported high internal consistency for the IES-R, with coefficient alphas ranging from 0.87 to 0.92 for intrusion, 0.84 to 0.85 for avoidance, and 0.79 to 0.90 for hyperarousal. Test-retest correlation coefficients ranged from 0.57 to 0.94 for intrusion, 0.51 to 0.89 for avoidance, and 0.59 to 0.92 for hyperarousal.

## **Procedure**

Ethics approval for the study was obtained from the Northern X Regional Ethics Committee, the Manukau District Health Board Research Ethics Committee (MDHBRC), and the Maori Research Review Committee (MRRC).

Participants were mailed out a survey package which included (1) a cover letter outlining the study, describing its potential benefits to future breast cancer patients and providing a link to the survey monkey website for participants wishing to complete the questionnaire online; (2) a participant information sheet outlining the purpose of the study in more detail, assurance of confidentiality, the requirements of participation, what will happen at the end of the study, potential risks of the study, how to access psychological assistance and how to obtain further information (see Appendix C) ; (3) a consent form to be signed (see Appendix B); (4) the pilot questionnaire; and (5) a stamped envelope addressed to the researcher.

## **Statistical Analyses**

All statistical analyses were conducted using SPSS version 20.

### ***Exploratory factor analysis***

Principal components analysis was performed to examine the underlying factor structure of the coping items, assessing whether they represented the various coping constructs as hypothesised. A full exploratory factor analyses of the measure was not conducted due to the current sample size violating the underlying assumptions for this test. A ratio of 5 cases per coping item is recommended for an exploratory factor analyses (Palant, 2011).

Data included in the factor analysis was limited to respondents who indicated that they experienced cancer worry and subsequently completed the 'Coping with Worries of

Cancer Recurrence Scale'. Prior to factor extraction, assumptions underlying factor analysis and the correlations matrices were examined to verify significant correlations of 0.3 and above for each coping domain.

Subsequently, a Principal Components Analysis was performed on items hypothesised to fall under each coping construct. Prior to final items being selected under each domain, there was an examination of the eigenvalue statistic and the scree plot to ensure that only a single factor was captured. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) and Bartlett's Test of Sphericity was also used to verify that data was suitable for Factor Analysis. A KMO of greater than 0.5 is recommended for a satisfactory factor analysis to proceed (Field, 2009).

Factor rotations of each coping construct was conducted to aid interpretation of item loadings on factors. In the current analyses, oblique rotation, using the direct oblimin method was chosen due to significant correlations among coping items. Items that did not load clearly onto factors were considered for removal from the final scale.

Several criteria were implemented in the selection of final items for each subscale. Initially, factor loadings of items on each factor of 0.4 or above were essential. In the event that items loaded highly on more than one factor, the meaning of the item was considered and it was placed under a subscale that best captured the coping strategy. Items that did not load clearly or highly on factors (eg. less than  $|0.40|$ ) were removed, especially if mean ratings indicated that the particular strategy was underutilised by the majority of participants.

Finally, item analyses were conducted in which the internal reliability of respective subscales was calculated with items of low factor loadings included and excluded. The outcomes of these analyses combined with the fit of the items within the subscale were then evaluated to determine which items were kept or removed from the final subscale. Items that increased alpha significantly when excluded from the analysis were considered for removal

from the final subscale, particularly if they yielded relatively low factor loadings. However, some cases they were retained to provide further information regarding its use as a coping strategy by participants in the main study. Conversely items which decreased alpha when eliminated from the analysis were retained in the final subscale. Furthermore, it was noted that small subscales comprising of only 2 or 3 items yielded low Cronbach Alpha values of below 0.5. As a consequence additional items that captured the underlying construct were added to the subscale. These items were obtained from free responses generated from participants and the literature.

### ***Reliability and Validity Analyses***

Subsequent to factor analysis, the reliability and validity of each subscale was evaluated. Reliability analysis involved calculating each subscale's internal consistency to ensure that items comprising respective subscales were measuring the same underlying construct. Cronbach's Alpha coefficients provided an indication of the internal consistency of each subscale with an  $\alpha$  of 0.7 and above being ideal (George & Mallery, 2003). The convergent and discriminant validity of the coping subscales were evaluated through correlational analyses with other theoretically similar and dissimilar constructs. Convergent validity was indicated by medium to high correlations between subscales and conceptually related measures while discriminant validity was suggested by non-significant correlations with conceptually unrelated measures. Pearson correlations were also used to evaluate the relationships between cancer worry and the varying coping strategies. Analyses utilized a significance level of  $p < .05$ . As indicated by the literature, it was predicted that worries of cancer recurrence would be strongly associated with levels of depression, anxiety, avoidance, intrusions and hypervigilance. In order to assess if the findings of the current pilot study were consistent with research, correlational analysis was conducted between worry of cancer

recurrence scores and participant scores on relevant subscales comprising the Hospital Anxiety and Depression Scale and The Impact of Events Scale (Revised).

## CHAPTER III: PILOT RESULTS

### Overview

The purpose of the pilot study was to develop and validate a coping with worry of breast cancer recurrence measure and explore the relationship between different coping styles and levels of cancer worry. The initial coping measure was created using the coping styles highlighted in the Common Sense Model and breast cancer literature. This chapter outlines the selection process for items comprising each coping subscale of the final Coping with Worry of Breast Cancer Recurrence Measure as well as the selection of additional coping items for further analysis in the main study. Between 50 and 52 respondents completed each subscale of the coping measure after indicating that they experienced worries of cancer recurrence. Initially, each subscale was subjected to factor analysis to ensure that only a single factor was extracted and each item loaded sufficiently onto this factor as hypothesised. Subsequently, the internal consistency of each construct or subscale was evaluated and items were deleted, retained or additional items were added to provide additional information in the main study. The convergent and discriminant validity of each subscale was also tested using the other subscales and measures of anxiety, depression, avoidance, hyperarousal and intrusions. Finally, the relationship between coping subscales and levels of cancer worry was evaluated.

### Factor Analyses

Prior to the analysis, the suitability of the data for factor analysis was determined. Pallant (2011) recommends a minimum of 5 cases per item as an assumption for Factor Analysis; this appeared to be satisfied for each coping subscale as a minimum of 50 participants responded to each subscale item. The outcomes of each factor analysis and final items comprising each subscale are presented below. Each subscale corresponds to one of

seven coping constructs including: spiritual coping, suppression, expression, problem solving, positive thinking, healthy living and distraction.

***Subscale structure of the Coping with Worry of Cancer Recurrence Measure***

*Problem Solving.* Item means suggested that most women used problem solving strategies ‘*sometimes*’ to cope with their worry of cancer recurrence (see Table 3-1). Inspection of the Kaiser-Meyer-Olkin statistic ( $KMO = 0.765$ ) and Bartlett’s test of sphericity ( $71.04, df = 10, p < 0.01$ ) suggested factorability of the subscale. Following Principal Components Analysis a single factor of eigenvalue 2.68, explaining 53.67% of the variance was extracted. In comparison to the final four items of the subscale, it was noted that the ‘I check myself for symptoms or signs that the cancer has returned’ item generated a significantly lower loading. A reliability analysis was conducted to evaluate the internal reliability of the subscale and the potential removal of item 1. An  $\alpha$  of 0.76 was obtained with all 5 items included, suggesting acceptable internal consistency. However exclusion of item 1, ‘I check myself for symptoms or signs that the cancer has returned,’ resulted in a slight increase of  $\alpha$  to 0.79, approaching a good level of internal consistency. Despite this, the item was reworded to ‘I check myself for lumps or other signs of cancer’ and retained in the final subscale. This was a consequence of an adequate internal consistency with the item retained, only a minimal increase in  $\alpha$  if excluded and item 1 being utilised more by women as compared to the other subscale items (see Table 3-1). Inclusion of the item in the final subscale was also substantiated by examination of the literature and free responses generated in the questionnaire which highlighted frequent checking behaviours in women, particularly in reference to ‘lumps’.

Table 3-1. *Mean (M), Standard Deviation (SD) and Factor Loadings for items relating to Problem Solving*

Items	<i>M</i>	<i>SD</i>	Factor Loadings
1. I check myself for symptoms or signs that the cancer has returned	2.49	0.86	.47
2. I think through what might happen if it does come back	2.08	0.66	.86
3. I think through the reasons why the cancer may or may not come back	2.10	0.81	.78
4. I focus on a strategy of coming up with what to do	1.84	0.90	.79
5. I focus on thinking about it	1.55	0.64	.70

*Distraction.* Item means suggested that most women used distraction strategies at least ‘sometimes’ to cope with worries of recurrence (see Table 3-2). Inspection of the Kaiser-Meyer-Olkin statistic ( $KMO = 0.50$ ) and Bartlett’s test of sphericity ( $7.84, df = 1, p < 0.01$ ) indicated that the subscale was only minimally subjectable to a factor analysis. Following Principal Components Analysis, a single factor of eigenvalue 1.39, explaining 69.50% of the variance was extracted. Inspection of table 3-2 indicated that the both items loaded highly onto the extracted factor. There were too few items to conduct a reliability analysis, however due to strong loading and contribution to the meaning of the subscale, both items were retained in the final subscale. A further item was added, ‘I turn my focus to other things,’ due to the low number of subscale items, free responses pertaining to distractive coping and its applicability to the subscale. Finally, the second, ‘item I distract myself by doing something else (work or other activities)’ was amended slightly in the final subscale to, ‘I distract myself by doing something else,’ to capture a range of activities other than work.

Table 3-2. *Mean (M), Standard Deviation (SD) and Factor Loadings for items relating to Distraction*

Items	<i>M</i>	<i>SD</i>	Factor Loadings
1. I try to ignore or push these thoughts out of my mind	2.92	1.01	.83
2. I distract myself by doing something else (work or other activities)	2.80	1.05	.83

*Optimistic Thinking.* Table 3-3 presents the means (*M*), standard deviations (*SD*) and the factor loadings of all 3 items. Item means suggest that most women use optimistic thinking strategies ‘*sometimes*’ or ‘*most of the time*’ to cope with their worries of cancer recurrence. Inspection of the Kaiser-Meyer-Olkin statistic ( $KMO = 0.67$ ) and Bartlett’s test of sphericity ( $51.20, df = 3, p < 0.01$ ) suggested factorability of the subscale. Following Principal Components Analysis a single factor of eigenvalue 2.15, explaining 71.54% of the variance was extracted. Inspection of table 3-3 indicated that all 3 items yielded reasonably high loadings on the extracted component. Following a reliability analysis of the subscale, an  $\alpha$  of 0.79 was obtained suggesting acceptable to good internal consistency. Exclusion of items 1 and 3 from the reliability analysis resulted in a significant reduction in  $\alpha$  below acceptable levels while exclusion of item 2 yielded an  $\alpha$  level indicative of good internal consistency. However, following inspection of the mean for item 2 (see Table 3-3), ‘I focus on the positive aspects of my experience with cancer’, this item was retained given that most women tended to use this strategy ‘most of the time’. Retention of this item was also supported by its high loading on the optimistic subscale and its contribution to the meaning of the positive thinking subscale. It should also be mentioned that while item 1, ‘I reassure myself that I’m fine, healthy and strong’ was retained due to its high loading, high usage as a coping strategy, contribution to internal consistency and meaning to the subscale, it was reworded to ‘I tell myself that I’m being silly and that I’m fine, healthy and strong’. The rewording of the item

seemed appropriate given that the term “reassure” may suggest an element of attempted self-deception about one’s health.

Table 3-3. *Mean (M), Standard Deviation (SD) and Factor Loadings for items relating to Optimistic Thinking*

Items	<i>M</i>	<i>SD</i>	Factor Loadings
1. I reassure myself that I’m fine, healthy and strong	3.25	0.88	.90
2. I focus on the positive aspects of my experience with cancer	3.10	1.03	.78
3. I tell myself that I can handle it if the cancer comes back	2.81	1.10	.86

*Spirituality.* The factorability of the spiritual coping subscale was confirmed by a Kaiser-Meyer-Olkin value of 0.79, a significant Bartlett’s test of sphericity (260.26,  $df = 0.15$ ,  $p < 0.01$ ) and via inspection of the correlation matrix indicating correlations of above 0.4. As predicted, only one factor was extracted; Kaiser’s Criterion indicated a single factor with an eigenvalue of 4.32, explaining 71.94% of the variance; examination of the scree plot indicated a clear break between the first and second components. Table 3-4 presents the means (*M*), standard deviations (*SD*) and the factor loadings of the subscale items. All 6 items yield very high factor loadings of above 0.8. Item means indicate that most women identified using spirituality for cancer worries ‘*almost never*’ or ‘*sometimes*’. Prior to a final decision of items comprising this subscale, a reliability analysis was conducted yielding an  $\alpha$  of 0.92, suggesting excellent internal consistency. The analysis also confirmed that deletion of any single item would result in a decrease in alpha and the consistency of the subscale. As a consequence, all 6 items were retained in the final subscale.

Table 3-4. *Mean (M), Standard Deviation (SD) and Factor Loadings for items relating to Spirituality*

Items	<i>M</i>	<i>SD</i>	Factor Loadings
1. I go to my place of worship (church, temple. etc)	1.39	0.80	.87
2. I ask others to pray for me	1.37	0.80	.82
3. I trust in god to help me cope	2.00	1.22	.82
4. I focus on the spiritual aspects of my experience	1.86	1.04	.87
5. I go to places where I can connect with my spirituality	1.63	0.89	.81
6. I pray	1.86	1.08	.89

*Expression.* Most women identified using expression strategies ‘almost never’ to ‘sometimes’ to cope with cancer worries (see Table 3-5). Factor analysis was conducted following inspection of the Kaiser-Meyer-Olkin statistic ( $KMO = 0.690$ ) and the Bartlett’s test of sphericity ( $139.44, df=15, p < 0.01$ ) which indicated the factorability of the subscale. Following Principal Components Analysis only 1 factor of eigenvalue of 3.35, explaining 55.75% of the variance, was extracted. As indicated in Table 3-5, all items had reasonable to high loadings on this component. Reliability testing of all six items comprising the subscale yielded an  $\alpha$  of 0.84 suggesting good internal reliability. The analysis also indicated that elimination of any single item resulted in a reduction of Alpha and the internal reliability of the subscale. Overall, and as a consequence of adequate loading and good internal consistency all items were retained in the final subscale.

Table 3-5. Mean (*M*), Standard Deviation (*SD*) and Positive Factor Loadings for items relating to Expression

Items	<i>M</i>	<i>SD</i>	Factor Loadings
1. I talk to a friend, partner or family member about it	1.76	0.79	.68
2. I let others know how I feel	1.65	0.74	.76
3. I write about it	1.22	0.64	.61
4. I ask for advice from my family, partner or friends	1.61	0.89	.90
5. I seek out sympathy and understanding from others	1.55	0.88	.79
6. I seek physical affection such as hugs from my family, partner or friends	2.20	1.02	.71

*Suppression.* Table 3-6 presents the means (*M*), standard deviations (*SD*) and the factor loadings of suppression coping items. Inspection of the means indicated that most women identified using suppression strategies at least ‘*sometimes*’ to cope with cancer worries. Prior to conducting the factor analysis, a Kaiser-Meyer-Olkin value of .63 and a significant Bartlett’s test of sphericity (77.06,  $df = 3$ ,  $p < .01$ ) confirmed the factorability of the subscale. The correlations matrix also yielded acceptable correlations of above .47. Factor analysis confirmed that all three items loaded onto a single factor of eigenvalue 2.23, explaining 74.39% of the variance. As is evident from inspection of Table 3-6, all 3 items reveal high factor loadings, with the first two items loading slightly higher than item 3. A reliability analysis was conducted on the 3 subscale items yielding an  $\alpha$  of 0.80. While this suggested good internal consistency reliability,  $\alpha$  increased to 0.93 indicating an excellent level of internal consistency, if the ‘I smother my feelings’ item was removed from the analysis. Conversely,  $\alpha$  was noted to decrease substantially to below 0.7, to a questionable level of consistency if either of the first 2 items were removed. However, taking into account the small size of the subscale, the high loading of item 3, the ability of this item to capture the

meaning of the construct and a good level of internal consistency with item 3 included, item 3 was retained in the final subscale. This item was also noted to be used as a coping strategy by most women at least ‘Sometimes’ to cope with their cancer worries.

Table 3-6. Mean (*M*), Standard Deviation (*SD*) and Negative Factor Loadings for items relating to Suppression

Items	<i>M</i>	<i>SD</i>	Factor Loadings
1. I hide those feelings from others	3.38	0.77	.93
2. I keep it to myself	3.29	0.85	.91
3. I smother my feelings	2.83	1.02	.73

*Healthy Living.* Data analyses indicated that most women used the first two items comprising the healthy living subscale ‘most of the time’ to cope with worries of recurrence and the final item ‘Sometimes’ (see Table-3-7). Inspection of the Kaiser-Meyer-Olkin statistic ( $KMO = 0.61$ ) and Bartlett’s test of sphericity (24.28,  $df = 3$ ,  $p < 0.01$ ) suggested factorability of the subscale. Following Principal Components Analysis, a single factor of eigenvalue 1.81, explaining 60.19% of the variance was extracted. However, inspection of table 3-7 indicated that the first two items yielded significantly higher loadings compared to the third item, ‘I do things that help me relax, such as deep breathing, yoga, etc.’ As a consequence, a reliability analysis was conducted to evaluate the internal consistency of the subscale with the final item retained and excluded. An  $\alpha$  of 0.67, a questionable level of internal consistency was yielded when item 3 was included in the analysis. However,  $\alpha$  increased 0.72, an adequate level of internal consistency when the item was excluded. Given the outcome of this analysis and the relative low factor loading of item 3, it was eliminated from the final subscale. However, it was retained in the final coping measure to evaluate its use by participants in the main study. This was due to most women using this strategy to

some degree, ie. *sometimes*, (see Table 3-7) and references to this coping strategy in the free responses generated by participants. However, the wording of item 3 was amended slightly to ‘I practise deep breathing exercises, yoga or meditation’ to remove the assumption that women use this strategy only as a means of relaxation as opposed to for health reasons as well. Two more items were added to the subscale given it currently only composed of two items and due to its adequate level of internal consistency. These additional items included ‘I go for walks’ and ‘I try to get enough sleep’. These were obtained from the free responses generated by participants and because they appeared to meaningfully capture the construct of healthy living.

Table 3-7. *Mean (M), Standard Deviation (SD) and Factor Loadings for items relating to Healthy Living*

Items	<i>M</i>	<i>SD</i>	Factor Loadings
1. I try to eat a healthier diet	3.02	1.04	.84
2. I try to include exercise in my daily routine	3.00	1.05	.82
3. I do things that help me relax, such as deep breathing, yoga, etc.	2.04	0.99	.65

### **The Coping with Worry of Cancer Recurrence Measure (Revised)**

The 7 subscales and related items comprising the final measure have been outlined above. However, it is important to point out that 5 additional items were also added to the initial pilot coping measure to evaluate the extent to which women used these strategies to cope with worries of cancer recurrence. Following this analysis, the decision to retain or delete them from the final measure was carefully evaluated. The means (*M*) and standard deviations (*SD*) pertaining to these items are presented in Table 3-8.

Table 3-8. *The Mean (M) and Standard Deviation (SD) for items of insufficient loading or lack of meaningfulness to final subscales*

Items	<i>M</i>	<i>SD</i>
1. I try to laugh it off	2.13	.99
2. I use alcohol or drugs to help me cope	1.10	.30
3. I comfort myself by eating food	1.48	.64
4. I look for more information about cancer or cancer recurrence	1.98	.03
5. I visit my doctor	1.67	.89

Item 1, ‘I try to laugh it off’ was retained in the revised measure as most participants tended to use this strategy at least ‘*sometimes*’. Two further items, ‘I make jokes about it’ and ‘I make fun of the situation’ were added to the revised coping measure to assess the extent to which women used humour as a coping strategy. These items were adapted from Carver’s ‘Brief Copc’ measure (Carver, 1997). It is anticipated that these 3 items may be captured in a further subscale of ‘humour’ in the factor analysis of the revised coping measure.

Item 2, ‘I use alcohol or drugs to help me cope’ was deleted from these measure as none of the respondents reported using it ‘*most of the time*’ or ‘*almost always*’. However, for the purposes of evaluating the extent to which women used substances to cope, two additional items were added to the revised measure. The wording of these items, ‘I use alcohol or drugs to help me get through it’ and ‘I use alcohol or drugs to make me feel better’ were hypothesised to more adequately capture the concept of using alcohol and/or drugs as a coping strategy. Similarly, items 3 and 4, ‘I comfort myself by eating food’ and ‘I look for more information about cancer or cancer recurrence’ were retained in the revised measure to

evaluate the extent to which women utilised these strategies in the main study. Although it may be important to note that none of the participants reported using the, ‘I comfort myself by eating food,’ strategy ‘*almost always*’ as a coping mechanism. Finally, item 6, ‘I visit my doctor’ was slightly amended to, ‘I go to a doctor or health care professional for an examination to make sure the cancer hasn’t returned’ and retained in the revised measure for further evaluation in the main study. It was hypothesised that the new wording was more specific in relation to seeking help from medical professionals to cope with worries of recurrence. Please see Table 3-9 for a list of the final 39 items pertaining to the Coping with Worries of Cancer Recurrence Measure (Revised).

Table 3-9. *Coping with Worries of Cancer Recurrence Measure (Revised)*

Items
<i>Problem Solving</i>
I check myself for lumps or other signs of cancer
I focus on thinking about it
I think through the reasons why the cancer may or may not come back.
I think through what might happen if it does come back
I focus on coming up with a strategy of what to do
<i>Distraction</i>
I distract myself by doing something
I try to ignore or push these thoughts out of my mind
I turn my focus to other things
<i>Optimistic Thinking</i>
I focus on the positive aspects of my experience with cancer
I tell myself that I’m being silly and that I’m fine, healthy and strong.
I tell myself that I can handle it if the cancer comes back
<i>Spirituality</i>
I pray
I ask others to pray for me

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I go to my place of worship (church, temple. etc)

I trust in god to help me cope

I focus on the spiritual aspects of my experience

I go to places where I can connect with my spirituality

*Expression*

I talk to a friend, partner or family member about it

I write about it

I let others know how I feel

I seek physical affection such as hugs from my family, partner or friends

I ask for advice from my family, partner or friends

I seek out sympathy and understanding from others

*Suppression*

I keep it to myself

I hide those feelings from others

I smother my feelings

*Healthy living*

I go for walks

I try to get enough sleep

I try to eat a healthier diet

I try to include exercise in my daily routine

*Humour (new)*

I try to laugh it off

I make jokes about it

I make fun of the situation

*Substances Coping (new)*

I use alcohol or drugs to help me get through it

I use alcohol or drugs to make me feel better

*Additional Items*

I practise deep breathing exercises, yoga or meditation

I comfort myself by eating food

I look for more information about cancer or cancer recurrence

I go to a doctor or health care professional for an examination to make sure the cancer hasn't returned

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### *Convergent and discriminant validity*

The convergent and discriminant validity of the subscales comprising the Coping with Worries of Cancer Recurrence were assessed to ensure that they were measuring distinctive coping strategies. This involved a correlational analysis of the relationships between the coping subscales respectively and measures of anxiety, depression, worry of cancer recurrence, intrusions, avoidance and hyper-arousal. To assess convergent and discriminant validity there was an inspection of the directionality and significance of the Pearson's correlations, indicating the relationship between respective subscales and those measures or subscales that they should and should not be theoretically related to. The outcomes of this analysis are presented in Table 3-10.

It was predicted that there would be a large negative correlation between the suppression and expression subscales given that they represented opposing coping strategies. As predicted, higher levels of expression were significantly associated with lower levels of suppression ( $r = -.67, p < .01$ ). Given that spirituality is a form of expression, there was also a prediction of a positive correlation between spirituality and expression, and conversely, a negative relationship between spirituality and suppression. This was confirmed with medium sized correlations between spiritual coping and the expression ( $r = .44, p < .01$ ), and suppression subscales ( $r = -.42, p < .01$ ) respectively. In addition, there was a prediction of a negative relationship between optimistic thinking and anxiety which was substantiated by results indicating a medium sized correlation between these subscales ( $r = -.31, p < .05$ ). Finally, discriminant validity was suggested by a lack of correlation between subscales and other theoretically unrelated subscales or measures. For example, as predicted there was no correlation between spirituality and healthy living ( $r = .00, p > .05$ ) or distraction ( $r = .00, p > .05$ ).

Table 3-10. Pearson ' Correlations between Coping Subscales Respectively and Measures of Anxiety, Depression and Post-Traumatic Symptoms

Scale	Problem Solving	Distraction	Optimistic Thinking	Spirituality	Expression	Suppression	Healthy living
Problem Solving	1.00						
Distraction	-0.16	1.00					
Optimistic Thinking	-0.12	0.24	1.00				
Spirituality	0.24	0.00	0.12	1.00			
Expression	0.27	-0.04	-0.04	<b>0.44**</b>	1.00		
Suppression	<b>-0.29**</b>	0.22	0.17	<b>-0.42**</b>	<b>-0.67**</b>	1.00	
Healthy living	0.00	0.12	0.11	0.00	0.13	-0.01	1.00
Depression	0.13	-0.20	-0.27	0.00	0.00	-0.04	-0.24
Anxiety	0.17	-0.16	<b>-0.31*</b>	0.00	0.06	0.04	0.07
Avoidance	<b>0.32*</b>	-0.01	-0.09	0.26	0.08	0.05	0.02
Intrusions	0.20	-0.02	-0.15	0.11	0.07	0.11	0.07
Hyperarousal	0.23	-0.08	-0.04	0.22	0.14	0.03	0.06
Worry Of Recurrence	<b>0.37**</b>	-0.03	-0.23	<b>0.29*</b>	0.23	-0.16	0.20

## **Worry of Cancer Recurrence**

McCaul's Brief Worry Measure was used to evaluate worry of cancer recurrence (FoR) in participants. Prior to obtaining a final FoR score for each participant, the fourth item comprising the measure, 'to what extent are you confident that your body can control your cancer and stop it from spreading?' was reverse scored and the internal consistency of the four items relating to FoR was calculated.

The analysis yielded an  $\alpha$  of 0.81 suggesting good internal consistency. However, it was noted that  $\alpha$  increased significantly to 0.89 when the 'to what extent are you confident that your body can control your cancer and stop it from spreading?' item was removed from the analysis. As a consequence, this item was not included in the final FoR score for each participant. This score of cancer worry was used in the analysis of the relationship between FoR and respective coping subscales, and finally with measures of depression, anxiety, intrusions, avoidance and hyperarousal.

### ***The relationship between worry of cancer recurrence and coping subscales***

These results indicated two significant correlations, that between worries of cancer recurrence and the spiritual coping ( $r = .29, p < .05$ ) and problem solving ( $r = .37, p < .01$ ) subscales (see Table 3-10). This analysis appeared to indicate that higher levels of spiritual and problem solving coping strategies were associated with higher levels of cancer worry. These preliminary indications of the relationship between coping and worries of cancer recurrence will be further evaluated in the final study incorporating a larger number of participants and the revised coping scale. Overall, the findings suggest that the coping subscales are distinct from overall worry about cancer recurrence; use of these strategies varies independently of the levels of recurrence worry.

***The relationship between worry of cancer recurrence and measures of depression, anxiety, avoidance, intrusions and hypervigilance***

Consistent with the literature, Pearson's correlational analysis yielded significant, positive relationships between levels of cancer worry and measures of depression, anxiety, avoidance, intrusions and hypervigilance (see Table 3-11). This suggested that high levels of cancer worry were associated with greater levels of depression, anxiety, avoidance, intrusions and hypervigilance.

Table 3-11. *Correlation between Worry of Cancer Recurrence and Measures of Anxiety, Depression, Avoidance, Intrusions and Hypervigilance*

Measure	Pearson's Correlation
Anxiety	.54**
Depression	.47**
Avoidance	.56**
Intrusions	.69**
Hypervigilance	.61**

### **Summary**

Consistent with hypothesis 1, all items pertaining to each subscale of the 'Coping with Worry of Cancer Recurrence' measure rotated onto a single factor as expected. Convergent validity of the new measure was also confirmed by the predicted pattern of significant correlations between relevant subscales and measures, while discriminant validity was established by the lack of any significant relationship between unrelated constructs.

The final 'Coping with Worry of Cancer Recurrence' measure (see Appendix A2) consists of the original seven subscales of: problem solving, distraction, optimistic thinking, spirituality, expression, suppression and healthy living; and two new subscales; humour and substances coping. It also contains four additional items for further analyses: 'I practise deep

breathing exercises, yoga or meditation;’ ‘I comfort myself by eating food;’ ‘I look for more information about cancer or cancer recurrence;’ and ‘I go to a doctor or health care professional for an examination to make sure the cancer hasn’t returned.’ This adjusted measure will be used in the main study to examine relationships between women’s coping and their level of worry of recurrence concurrently and over the period of a month. Women’s use of avoidance coping will also be included in this analyses and will be assessed using the Impact of Events Scale Revised.

Finally, women’s level of worry of recurrence in the main study will be calculated using the first three items of McCaul’s Brief Worry Measure (McCaul et al., 1998) measure: (1) How worried are you about having a recurrence of breast cancer?; (2) How concerned are you about having a recurrence of breast cancer?; and (3) How much does thinking about a recurrence of breast cancer bother you? This is a consequence of the outcomes of the test of internal consistency of worry items demonstrated in this study.

## CHAPTER IV: METHODS

### Study Design

The current study was longitudinal in nature consisting of two questionnaires completed a month apart. The purpose of the longitudinal survey was to examine the relationships between worry of cancer recurrence and various psychological constructs including anxiety, depression, quality of life, intrusions, avoidance, hyperarousal and illness representations, including cancer image groups. In addition, the study was designed to evaluate whether various coping strategies predict women's worries of cancer recurrence both concurrently and over the short term. Women's coping strategies were assessed using the new 'Coping with Worry of Cancer Recurrence' measure validated in the pilot study and the avoidance subscale of the Impact of Events Scale Revised. The influence of age, cancer treatment, trait anxiety and time since diagnosis on associations between worry of recurrence and relevant constructs was also examined through inclusion of these variables as covariates.

### Participants and Procedure

A total of 143 women were recruited using the New Zealand Cancer Registry (NZCR), which was used to identify all women diagnosed with primary breast cancer in the Auckland region in the last five years. Recruitment was limited to the Auckland region for the purpose of ease of access to participants in the event that the study caused women distress. Inclusion criteria for the main study included the following: (a) Age of 18 years and over; (b) Treatment for primary breast cancer within the last three years; (c) No cancer recurrence following treatment; and (d) Not currently undergoing treatment for major depression or other psychological disorders. Women with current diagnosis were excluded from the current study due to concerns about participation potentially exacerbating their distress.

A total of 400 women were invited to participate in the study, with 140 women completing the questionnaires across both time points. Three participants completed the questionnaire at Time 1 but failed to complete and submit the second questionnaire a month later. The final response rate of the study was therefore 35.8%, with a completion rate of 97.9%. It was not possible to ascertain the proportion of women who had been invited to the current study but who could not be reached because of a change of address or those who had passed away. None of the women who were recruited into the study experienced a cancer relapse over the duration of the study.

The demographic characteristics of participants are presented in Table 4-1. Participants included women aged between 33 and 77 years old and of predominantly New Zealand European and Maori descent. Most women were married or co-habiting with a partner and a majority had children. The proportion of women across each income group was comparable suggesting a diverse sample in terms of socioeconomic status.

Table 4-1. *Demographic Characteristics of the Sample*

Variable	Total	Percentage
<i>Ethnicity (N = 143)</i>		
NZ Maori	21	14.69
NZ European / Pakeha	104	72.73
Asian	4	2.80
Indian	2	1.40
Pasifika	2	1.40
Other	10	6.99
<i>Women with Children (N = 143)</i>		
Yes	123	86.01
No	20	13.99
<i>Marital Status (N = 143)</i>		
Married or Living With Partner	107	76.22
Single	8	5.59

Divorced or Separated	18	12.59
Widowed	10	6.99
<i>Income Level (N = 133)</i>		
Less than \$40,000	38	28.57
\$40,001 - \$60,000	20	15.04
\$60,001 - \$80,000	26	19.55
\$80,001 - \$100,000	22	16.54
\$100,001 or above	27	20.30
<i>Education Level (N = 134)</i>		
Year 9 / Year 10	20	14.93
Form 5 / Form 6	31	23.13
Form 7	11	8.21
Trade Certificate/ National Certificate/ Diploma	40	29.85
Bachelor's Degree/ Post Graduate Diploma	27	20.15
Masters Degree or PHD	1	0.75
Other	4	2.99

*Note.* For ethnicity, 'Other' includes British Caucasian, British Indian, South African, North American and people of mixed ethnicity.

Ethical approval from the Northern Regional Ethics Committee was obtained prior to recruitment. A dataset of women who had undergone treatment for primary breast cancer in the past five years was obtained from the New Zealand Cancer Registry (NZCR). Women who had undergone treatment in the last three years were contacted by mail and provided with information about the study (see Appendix E), an invitation to participate, a consent form (See Appendix D) and a postage paid return envelope. Materials outlined confidentiality, the voluntary nature of the study, the requirements of participation and information on how to access psychological assistance in the event of emotional upset. In addition, participants were asked to provide a codename to ensure their privacy and to choose the method with which they wished to be contacted; they were informed that this would be used to remind them to complete each questionnaire.

Women who consented to participate in the study were mailed the first questionnaire and then the second questionnaire a month later. They received reminders to return each questionnaire either by email, telephone contact or text message.

## **Measures**

The study measures are presented in Appendices A. The measures comprising the pilot study and each questionnaire of the main study is outlined in Table 4.2. The Brief Worry Measure, Hospital Anxiety and Depression Scale and Impact of Events Scale (Revised) were administered in the first questionnaire; Chapter 2 reports information pertaining to these measures. The first questionnaire also included measures of demographic characteristics (see Appendix A4), the adjusted Coping with Worry of Recurrence Measure (see Appendix A2), avoidance coping as measured by the Impact of Events Scale Revised, the Illness Perceptions Questionnaire Revised (see Appendix A11) (Moss-Morris et al., 2002), the Short Form 36 Quality of Life Measure (see Appendix A10) (Ware, 2004), the trait version of the State-Trait Anxiety Inventory (see Appendix A8) (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983) and the imagery subscale of the Assessment of Illness Risk Representations Measure (see Appendix A9) (Cameron, 2008). Descriptions and psychometric characteristics pertaining to these additional measures are presented in this chapter.

The second questionnaire was mailed to participants four weeks subsequent to completion of Questionnaire One. The following questions/measures were included in the questionnaire: Current Mental Health Status, a question pertaining to whether women had experienced a cancer recurrence in the past month and McCaul's Brief Worry Measure. Women were reminded to expect the questionnaire immediately following it being mailed to them and they were also contacted shortly after to ensure they had received the questionnaire.

Table 4.2. *Measures comprising the Pilot Study and Questionnaires of the Main Study*

Measures	Pilot Questionnaire	Questionnaire 1	Questionnaire 2
Brief Worry Measure	✓	✓	✓
Hospital Anxiety and Depression Scale	✓	✓	
Impact of Events Scale (Revised)	✓	✓	
Coping with Worry of Cancer Recurrence Measure	✓	✓	
Avoidance Coping (Measured by the Impact of Events Scale Revised)		✓	
Illness Perceptions Questionnaire (Revised)		✓	
Short Form 36 Quality of life measure		✓	
Spielberger's Trait Anxiety Measure		✓	
Adapted Imagery subscale of the Assessment of Illness Risk Representations Measure (AIRR)		✓	

### ***The Illness Perceptions Questionnaire Revised (IPQ-R)***

The Illness Perceptions Questionnaire Revised (Moss-Morris et al., 2002) was used to assess women's cognitions and emotions relating to their breast cancer. The IPQ-R subscales used in the current study included: acute/chronic timeline, consequences, personal control, treatment control, coherence, cyclical timeline, emotional representations and identity,

The identity subscale consisted of 24 symptoms commonly reported by breast cancer patients. Participants were asked to report whether they had experienced each of the symptoms in the past week (*yes* or *no*), and whether they believed the symptom was related to their breast cancer or cancer treatment (*yes* or *no*). The sum of the *yes* responses on the latter set of items formed the identity score. High scores thus reflect the number of symptoms perceived to be related to their breast cancer. The remaining timeline, consequences, control, coherence and emotional representation subscales consisted of items that were rated on a five point scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Subscale items were averaged to generate final scores.

The acute/chronic timeline subscale (seven items) assessed women's perceptions about the duration of their breast cancer, with high scores indicating beliefs that it is a more chronic, persistent disease. Similarly, high scores on the cyclical timeline subscale (four items) reflect perceptions that the breast cancer repeatedly comes and goes over time. The consequences subscale (six items) assesses beliefs about the severity of their breast cancer severity and its impact on their physical, psychological, emotional, economic and social functioning; higher scores reflect perceptions of greater disease severity and negative impacts.

The coherence subscale (five items) assessed women's beliefs that they understand their breast cancer, with high scores on this subscale indicating greater understanding of their illness. The personal control (six items) and treatment control (five items) subscales gauged women's perceptions of their own and their medical treatment's ability respectively, to control cancer progression. Greater perceptions of disease control or efficacy were indicated by higher scores on each subscale. The final subscale of emotional representations (six items) assessed women's emotional responses to their illness, including depression, worry and

anxiety. Higher scores on the emotional representations subscale were indicative of more negative emotional responses to breast cancer.

The IPQ-R has been demonstrated to exhibit satisfactory psychometric properties, including good internal consistency with  $\alpha$  ranging from .79 to .89 (Moss-Morris et al., 2002). The test–retest reliability of the IPQ-R data was also found to be acceptable, exhibiting stability for up to six months (Moss-Morris et al., 2002). In addition, the IPQ-R has been used extensively to quantitatively evaluate the illness representations of individuals with breast cancer and other chronic illnesses (Cameron et al., 2007; Timmers et al., 2008).

### *The Short Form 36 Quality of Life Measure*

The Short Form 36 (SF 36) measure was administered to assess mental and physical quality of life. It has been extensively used within the general population and to evaluate the impact of illness for a variety of different conditions including HIV, rheumatoid arthritis, renal disease, cardiovascular disease and cancer (Ware, 2004).

It is a 36 item questionnaire comprised of the following eight subscales: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional and mental health. The first four subscales comprise the physical health subscale while the last four subscales comprise the mental health subscale. Each subscale contains between two to 10 items, each rated using Likert scales. For the current analysis, separate scores for each subscale and total scores for the physical health and mental health subscales were calculated. Higher scores reflect better quality of life. It is also important to point out that the bodily pain subscale was reverse scored so higher scores were actually indicative of less pain.

The reliability of the SF-36, including internal consistency and test-retest reliability, have been demonstrated to be more than adequate (Ware, 2004). Most research has indicated reliability statistics of greater than .80 for the subscales (McHorney, Ware, Lu, &

Sherbourne, 1994) and exceeding .90 for total scores on the physical and mental health subscales (Ware, 2004). In addition, research has demonstrated acceptable levels of concurrent, content, criterion, construct and predictive validity of the SF-36 measure (Ware, 2004).

### ***The Spielberger Trait Anxiety Inventory***

Trait anxiety was assessed using Spielberger's 20 item Trait Anxiety Inventory (Spielberger et al., 1983). Each item is rated on a scale ranging from 1 (*not at all*) to 4 (*very much so*). Ratings are summed to generate scores ranging from 20 to 80 with higher scores indicating higher levels of trait anxiety. Studies have indicated satisfactory construct and concurrent validity as well as high internal consistencies of above .75 (Spielberger et al., 1983) and test-retest coefficients exceeding .65 (Quek, Low, Razack, Loh, & Chua, 2004).

### ***The Imagery Subscale of the Assessment of Illness Risk Representations***

The imagery subscale of the Assessment of Illness Risk Representations (AIRR) (Cameron, 2008) was used to measure the imagery contents of women's breast cancer representations prior to treatment. The following instructions were provided to assess women's cancer imagery before treatment:

“In this section we want to try and understand the mental images you had of your breast cancer prior to treatment. Many women have a mental image or picture in their minds of what their cancer “looks like” inside their bodies. It may be more of a symbolic or creative image that “pops into your mind” than a “realistic” or physically accurate image. We would like you to describe what this image looks like. You may like to describe aspects of this image including its color, texture, shape, size, position and whether or not it moves.”

Following this explanation, women were asked to describe their cancer images before treatment. The response was thematically analyzed (Pallant, 2011) and used to categorize women into one of three Cancer Image groups: No Image, Lump or Inert Object and Creature

like. Inter-rater reliability was calculated and a satisfactory Cohen's Kappa of 0.71 ( $p < .001$ ) was obtained (Buick, 1997). All discrepancies were resolved through rater discussion and agreement.

### **Statistical Analyses**

All analyses were conducted using SPSS Version 20. For all statistical tests,  $p$ -values (two-tailed) of less than .05 were regarded as statistically significant. Bivariate correlations were conducted to examine: (1) the zero-order relationships between worry of cancer recurrence and age, treatment, trait anxiety, time since diagnosis, anxiety, depression, avoidance, intrusiveness, hyperarousal and quality of life; and (2) the zero-order relationships between worry of cancer recurrence and coping strategies.

One-way between-groups ANOVAs were used to compare the Cancer Image groups on their worry of cancer recurrence scores. Prior to testing, preliminary analysis indicated no violation of the assumptions underlying analysis of variance, including assumptions of normality and homogeneity of variance. Significant Cancer Image Group main effects were further evaluated using pairwise comparisons, using the Tukey HSD method for post hoc tests.

The Coping with Worry of Cancer Recurrence measure was subjected to principal components analysis with a direct oblimin rotation to evaluate if respective subscale items loaded onto one factor as predicted and with adequate factor loadings of above 0.4. Preliminary analysis was conducted to evaluate the suitability of the data for factor analysis. This included assessment of the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) and Bartlett's Test of Sphericity to determine if the correlation matrices were indeed factorable.

A principal components analysis was conducted for each of the original seven subscales comprising the measure including: 'spirituality', 'suppression', 'expression',

‘problem solving’, ‘optimistic thinking’, ‘healthy living’, ‘distraction’ and two new subscales; ‘humour’ and ‘substances coping’. Given amendments to the measure following the Pilot Study which included addition of new items, rewording of some subscale items and addition of the ‘humour’ and ‘substances’ subscales, it was important to evaluate if items loaded onto respective subscales as predicted. The same criteria for retaining or deleting items in the pilot study were adopted for the current analyses. This included taking into account factor loadings and the impact on the internal consistency of the subscale, if the item was removed from the analyses. Finally, total subscale scores were calculated for each participant, to be utilised in further statistical analyses.

Regression analyses were conducted to investigate: (1) whether age, treatment, trait anxiety and time since diagnosis predict worry of recurrence; (2) whether worries of cancer recurrence predict quality of life, anxiety and depression; (3) whether illness representations including image groups predict worry of recurrence; and (4) how different coping strategies predict worry of cancer recurrence concurrently and over a month, including how coping predicts changes in worry of recurrence over this period. Preliminary analyses were also conducted to ensure no violation of the assumptions underlying regression analyses including normality, linearity, multicollinearity and homoscedasticity. For each of the regression analyses, age, treatment (chemotherapy, hormonal treatment, surgery or radiotherapy), trait anxiety and time since diagnosis were included as covariates when preliminary analyses revealed that they were significant predictors of the dependent measure.

## CHAPTER V: RESULTS

### Overview

This chapter presents the results of analyses pertaining to the key hypotheses of the study as outlined in Section 8 of Chapter 1. These will be presented in six sections. The first section describes correlational analyses and an ANOVA analyses conducted as preliminary investigations of the relationships between worry of recurrence and measures of mental wellbeing, quality of life and illness representations (including cancer image groups). This section also presents results testing the hypotheses that higher levels of worry of recurrence will be associated with younger age, chemotherapy, hormonal treatment, higher levels of trait anxiety and a shorter time since diagnosis. A further standard regression analysis of these variables as predictors of worry of recurrence is evaluated in Section 2.

Section 3 presents the multiple regression analyses testing the hypotheses that worry of recurrence would predict higher levels of anxiety and depression, and poorer functioning on all domains of quality of life after controlling for age, treatment and trait anxiety. Section 4 examines the fourth set of hypotheses that higher scores on illness representation domains of identity, acute/chronic timeline, cyclical timeline, consequences and emotional representation will be associated with higher levels of worry of recurrence, while higher scores on the personal control, treatment control and coherence domains will be correlated with lower levels of worry of recurrence. In relation to cancer image groups, it was predicted that life like images with negative intent will be associated with more worry of recurrence compared to more benign cancer images. Finally, Section 5 describes the principal components analyses of the Coping with Worry of Cancer Recurrence Measure and the multiple regression analyses testing the predicted associations of coping strategies with worry of recurrence both concurrently and over the following month. Specifically, it was

hypothesized that greater use of avoidance, suppression, problem solving, distraction, and substance coping will be associated with higher levels of worry of recurrence, while expression, positive thinking, humour, healthy behaviours and spiritual coping will be negatively related to worry of recurrence. All of the findings of this study are summarized in Section 6 of this chapter.

### **Section 1: Correlational Relationships of Worry of Cancer Recurrence with Age, Treatment Type, Trait Anxiety, Mental Wellbeing, Quality of Life, and Illness Representations**

Table 5-1 presents the descriptive statistics and correlations for worry of cancer recurrence, age, treatment type, trait anxiety, time since diagnosis and measures of mental wellbeing. Worry of recurrence scores ranged between 0 and 18, with a mean of 8.52, suggesting that levels of worry of recurrence were moderate on average. In relation to treatment, 89.5% of women received surgery, 41.3% received chemotherapy, 62.9% received radiotherapy and 37.8% received hormonal treatment.

As hypothesized, there was a medium sized, negative correlation between age and worry of cancer recurrence indicating that younger age was associated with higher levels of worry of recurrence. Conversely, worry of recurrence was not associated with receipt of either surgery or radiotherapy. As hypothesized, positive correlations of worry of recurrence with chemotherapy and hormonal treatment indicated that women who had received chemotherapy or hormonal treatment experienced higher levels of worry of recurrence than their counterparts. In relation to time since diagnosis, contrary to prediction, there was no relationship between worry of recurrence and time since diagnosis. However, the mean time since diagnoses indicates that most women were two years post diagnosis on average during participation in the current study. Finally, as predicted, higher levels of trait anxiety were associated with higher levels of worry of recurrence. As a consequence of these findings, age, chemotherapy, hormonal treatment and trait anxiety were included as covariates in

subsequent multiple regression analyses investigating the relationships between worry of cancer recurrence and relevant constructs.

Worry of recurrence was positively associated with anxiety, depression, avoidance, intrusions and hyperarousal. These medium-sized, positive correlations are consistent with the predictions that higher levels of worry of cancer recurrence would be associated with poorer mental health scores.

There were also large correlations between the anxiety subscale and measures of depression, avoidance, intrusions and hyperarousal, indicating that higher levels of anxiety were related to more depression and post traumatic symptoms. In addition, higher levels of depression were associated with more hyperarousal. However, evaluation of the mean scores of anxiety, depression and post traumatic symptoms suggested most women scored fairly low on these indicators of poor psychological functioning.

Table 5-1 *Correlations between Worry of Cancer Recurrence and Age, Treatment Type, Trait Anxiety, and Measures of Mental Wellbeing*

	FoR	Age	Radiotherapy	Chemotherapy	Surgery	Hormonal Therapy	Trait Anxiety	Time Since Diagnosis	Anxiety	Depression	Avoidance	Intrusions	Hyperarousal
FoR	1												
Age	<b>-.33**</b>	1											
Radiotherapy	-.05	.04	1										
Chemotherapy	<b>.27**</b>	<b>-.40**</b>	.11	1									
Surgery	.11	-.14	<b>-.17*</b>	<b>.24**</b>	1								
Hormonal Therapy	<b>.17*</b>	-.11	.00	.08	.08	1							
Trait Anxiety	<b>.41**</b>	<b>-.24**</b>	.02	<b>.18*</b>	-.05	<b>.21*</b>	1						
Time Since Diagnosis	.12	.02	.02	-.02	-.02	-.09	.15	1					
Anxiety	<b>.48**</b>	<b>-.27**</b>	-.04	<b>.24**</b>	.01	.14	<b>.78**</b>	.05	1				
Depression	<b>.42**</b>	<b>-.21*</b>	.00	<b>.29**</b>	.02	.10	<b>.71**</b>	.11	<b>.65**</b>	1			
Avoidance	<b>.37**</b>	<b>-.22*</b>	.00	.05	-.02	.05	<b>.47**</b>	<b>.28**</b>	<b>.46**</b>	<b>.40**</b>	1		
Intrusions	<b>.49**</b>	<b>-.24**</b>	-.13	.10	.01	.17	<b>.52**</b>	<b>.18*</b>	<b>.66**</b>	<b>.43**</b>	<b>.62**</b>	1	
Hyperarousal	<b>.42**</b>	<b>-.23**</b>	-.06	.16	-.01	.11	<b>.53**</b>	.17	<b>.66**</b>	<b>.60**</b>	<b>.55**</b>	<b>.79**</b>	1
<i>M</i>	8.52	57.39	-	-	-	-	35.00	25.25	5.55	2.99	.91	.66	.39
<i>SD</i>	4.87	10.02	-	-	-	-	9.98	11.90	3.95	3.06	.82	.68	.58
<i>N</i>	143	137	143	143	143	143	138	128	141	142	138	140	138

Note. Significant statistics are bolded; \*\* p < .001; \* p < .05

Correlational analyses of the relationships between worry of recurrence and subscales of the SF36 (Table 5-2) revealed that, with the exception of physical functioning, worry of recurrence was negatively associated with all areas of physical and mental quality of life. Specifically small, negative correlations were found between cancer worry and the role physical, role emotional, social functioning and body pain domains (note that higher scores on the body pain scale correspond to lower pain levels). On the other hand, worry of recurrence exhibited higher negative correlations with the vitality, general health and mental health domains.

Total scores for the overall dimensions of physical and mental quality of life were also calculated by adding relevant subscale scores. Medium sized, negative correlations between worry of cancer recurrence scores and the physical and emotional dimensions suggested that higher levels of cancer worry were associated with lower scores on women's general physical and mental quality of life. Overall, outcomes of the preliminary correlational analyses were in line with the predicted relationships, with worry of cancer recurrence being associated with poorer quality of life.

Table 5-2. Correlations between Worry of Cancer Recurrence and Subscales of the SF36 Quality of Life

Scales	Physical Functioning	Role Physical	Role Emotional	Social Functioning	Body Pain	Vitality	Mental Health	General Health	Total Physical Health	Total Mental Health
FoR	-.15	<b>-.19*</b>	<b>-.26**</b>	<b>-.27**</b>	<b>-.25**</b>	<b>-.36**</b>	<b>-.37**</b>	<b>-.38**</b>	<b>-.31**</b>	<b>-.38**</b>
Physical Functioning	1									
Role Physical	<b>.51**</b>	1								
Role Emotional	<b>.46**</b>	<b>.61**</b>	1							
Social Functioning	<b>.48**</b>	<b>.51**</b>	<b>.62**</b>	1						
Body Pain	<b>.54**</b>	<b>.55**</b>	<b>.47**</b>	<b>.58**</b>	1					
Vitality	<b>.42**</b>	<b>.52**</b>	<b>.49**</b>	<b>.61**</b>	<b>.44**</b>	1				
Mental Health	<b>.30**</b>	<b>.30**</b>	<b>.57**</b>	<b>.62**</b>	<b>.32**</b>	<b>.69**</b>	1			
General Health	<b>.50**</b>	<b>.32**</b>	<b>.45**</b>	<b>.51**</b>	<b>.48**</b>	<b>.51**</b>	<b>.47**</b>	1		
Total Physical Health	<b>.83**</b>	<b>.76**</b>	<b>.64**</b>	<b>.65**</b>	<b>.75**</b>	<b>.63**</b>	<b>.45**</b>	<b>.78**</b>	1	
Total Mental Health	<b>.47**</b>	<b>.55**</b>	<b>.75**</b>	<b>.79**</b>	<b>.50**</b>	<b>.88**</b>	<b>.90**</b>	<b>.58**</b>	<b>.68**</b>	1
Mean	26.04	16.02	13.09	8.47	8.87	16.29	24.56	23.08	73.89	62.32
SD	4.17	4.22	2.60	1.96	2.01	4.37	4.46	4.74	11.97	11.38
N	141	140	141	142	141	143	143	139	132	140

Note. Significant statistics are bolded; \*\*  $p < .001$ ; \*  $p < .05$

Associations between women's mental representations of their breast cancer and levels of worry of recurrence were explored through correlational and, for cancer imagery, one way ANOVA analyses. Table 5-3 presents the means and correlations for the illness representation subscales. On average, scores for the consequences, personal control, treatment control and coherence domains were approximately moderate to slightly above moderate. On the other hand, scores on the acute/chronic timeline, cyclical timeline and emotional representations domains were less than moderate on average. For the identity domain, the mean score indicated that most women experienced few symptoms that they perceived were associated with a cancer recurrence.

As predicted, medium to large positive correlations indicated that higher levels of worry of recurrence were associated with perceptions of: a more chronic illness course, experiencing more cancer related symptoms, greater serious consequences, more unpredictable symptomology and poorer emotional responses. Negative correlations between cancer worry and domains of treatment control and coherence were also consistent with the hypothesis of lower levels of cancer worry being associated with perceptions of greater treatment efficacy and understanding of breast cancer. However, in contrast to prediction, there was no significant correlation between cancer worry and the personal control dimension of the IPQ-R.

Table 5-3. *Correlations between Worry of Cancer Recurrence and Illness Representation Attributes*

	Acute/Chronic Timeline	Consequences	Personal Control	Treatment Control	Coherence	Cyclical Timeline	Emotional Representations	Identity
FoR	<b>.49**</b>	<b>.50**</b>	<b>-.14**</b>	<b>-.38**</b>	<b>-.21*</b>	<b>.40**</b>	<b>.61**</b>	<b>.40**</b>
Acute/Chronic Timeline	1							
Consequence	<b>.50**</b>	1						
Personal Control	-.052	.013	1					
Treatment Control	<b>-.50**</b>	<b>-.35**</b>	<b>.20*</b>	1				
Coherence	<b>-.19*</b>	<b>-.20*</b>	.10	<b>.34**</b>	1			
Cyclical Timeline	<b>.55**</b>	<b>.43**</b>	-.07	<b>-.45**</b>	<b>-.31**</b>	1		
Emotional Representations	<b>.60**</b>	<b>.62**</b>	-.14	<b>-.52**</b>	<b>-.35**</b>	<b>.63**</b>	1	
Identity	<b>.35**</b>	<b>.39**</b>	.09	<b>-.26**</b>	-.15	<b>.42**</b>	<b>.36**</b>	1
Creature Like Image	.09	<b>.33**</b>	-.11	-.16	-.13	.09	<b>.36**</b>	<b>.19*</b>
Lump or Inert Image	-.09	<b>-.33**</b>	.11	.16	.13	-.09	<b>-.36**</b>	<b>-.19*</b>
<i>Mean</i>	2.18	3.04	3.19	3.89	3.64	2.33	2.80	4.22
<i>SD</i>	.78	.96	.82	.57	.86	.90	.94	4.46
<i>N</i>	139	138	138	139	139	139	139	141

Note. For all illness domains except identity, scores ranged from 1 to 5; all significant correlations are bolded, \*\* $p < .001$ ; \* $p < .05$

### ***Mental Cancer Imagery***

A total of 17 women did not respond to the imagery subscale and as a consequence were not included in the current analyses. Analyses of the cancer images held by participants prior to treatment revealed that 32.9% (N = 47) reported a creature-like image (e.g., I pictured it as a monster- green jelly like, about an inch, big with tentacles, warts and spots); 35.0% (N = 50) reported a lump or inert object (e.g., one big hard lump); and 20.3% (N = 29) reported no image. Table 5-4 presents examples of women's cancer images.

An ANOVA testing the differences in worry of recurrence among the three Cancer Imagery groups (No Image, Lump or Inert Object Image, and Creature-like Image) revealed a significant Cancer Imagery main effect;  $F(2, 123) = 7.20, p < .001$ , partial eta squared ( $\eta_p^2$ ) = .10. Post-hoc comparisons using the Tukey HSD test indicated that women in the Creature-like Image group reported greater worry of recurrence ( $M = 10.51, SD = 4.50, N = 47$ ) than did women in the No Image group ( $M = 6.93, SD = 5.33, N = 29$ ) and the Inert Lump or Object Image group ( $M = 7.50, SD = 4.36, N = 50$ );  $p$ 's  $< .05$ . The latter groups reported comparable levels of worry of recurrence. Overall, these findings are consistent with the hypothesis that women who have more malevolent images of their cancer experience greater levels of cancer worry. As the No Image and Lump or Inert Object groups did not differ in worry of recurrence, these groups were combined in subsequent analyses evaluating the independent relationships between having a creature-like image and worry of cancer recurrence, after taking other predictor variables into account.

Table 5-4. *Examples of Women's Cancer Imagery for each Image Group*

Lump or Inert Image	Creature Like Image
The cancer is a cyst; pink colour; texture soft; shape round; the position on the upper nipple and does not move.	A dark purple blob or stain, moving, slightly menacing, expanding and constricting trying to find a pathway to invade the pink healthy tissue of the rest of my body.
I am not a very creative person. I thought of it as just a lump, something that had to be cut out - probably just a harder bit of flesh.	I imagined the cancer deep dark and crawling through my body-spreading and invading at a rapid speed.
It was a tiny lump, probably black, in the top right area of the right breast. It was too small to feel.	It was green, black and had red and yellow eyes. It had no weapons apart from what came from inside it. I called it Cantankerous Stan.
Like a peanut in the husk, about an inch long, rectangle shape, firm like sinew, slightly movable, coloured reddish brown, not joined to other tissue so can be popped out like a pea in a shell.	Randomly scattered, aggressive, black, jagged, bigger than normal cells, like an anchored mother ship that sends out more dangerous poisonous black ugly razor sharp to cut into, infect and destroy the good passive other cells.
Firm round lump. When I see a golf ball I can picture that having been removed from my breast.	A little dot with tentacles that would reach out if not taken out and spit out when touched by the surgeon which is why I had radiation.
A three dimensional lump of an irregular uneven appearance.	I imagined it like a poisonous flower or shell - yellow and with tentacles spreading into my body.

## Section 2: Age, Treatment and Trait Anxiety as Predictors of Worry of Recurrence

Standard multiple regression was conducted to determine which of the variables of age, chemotherapy and hormonal treatment uniquely predicted worry of recurrence.

Age, Chemotherapy treatment, hormonal treatment, and trait anxiety explained 24.0%,  $F(4,128) = 10.03$ ,  $p < .001$ ) of the variance in worry of recurrence scores (see Table5-5). Results indicated that treatment variables of chemotherapy ( $\beta = .14$ ,  $p > .05$ ) and hormonal treatment ( $\beta = .07$ ,  $p > .05$ ) did not make a significant unique contribution to worry of recurrence scores. However, age ( $\beta = -.19$ ,  $p < .05$ ) and trait anxiety ( $\beta = .32$ ,  $p < .001$ ) were

found to be significant predictors of worry of recurrence, with trait anxiety making the largest contribution to worry of recurrence scores ( $\beta = .32$ ).

Table 5-5 *Multiple Regression Analysis of Age, Treatment and Trait Anxiety as Predictors of Worry of Cancer Recurrence*

	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>	<i>R</i> <sup>2</sup>	<i>F</i>
					.24	10.03**
Age	<b>-.09</b>	<b>.04</b>	<b>-.19</b>	<b>-2.16*</b>		
Chemotherapy	1.34	.83	.14	1.61		
Hormonal Treatment	.69	.79	.07	.88		
Trait Anxiety	<b>.16</b>	<b>.04</b>	<b>.32</b>	<b>3.96**</b>		

*Note.* Significant statistics are bolded; \*\* $p < .001$ , \* $p < .05$

### Section 3: Worry of Cancer Recurrence as a Predictor of Anxiety, Depression and Quality of Life

#### *Anxiety*

Hierarchical multiple regression was conducted to test whether worry of recurrence predicted general anxiety levels after controlling for trait anxiety. Preliminary analysis revealed that age and treatment were not significant covariates; thus both variables were removed from the final analysis (see Table 5-6). At Step 1, trait anxiety alone explained 61.0% of the variance in anxiety scores. Following entry of worry of recurrence scores at step 2, the total variance explained by the regression model was 64.2%  $F(2,133) = 119.50$ ,  $p < .001$ . Worry of cancer recurrence thus accounted for an additional 3.2% of the variance in anxiety scores  $R^2$  change = 0.03,  $F$  change (1, 133) = 12.01,  $p < .001$ . As hypothesized, worry of recurrence predicted higher levels of anxiety in this sample of breast cancer survivors.

Table 5-6 Multiple Regression Analysis of Worry of Recurrence as a Predictor of Anxiety

	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>	<i>R</i> <sup>2</sup>	<i>F</i>
Trait Anxiety	<b>.28</b>	<b>.02</b>	<b>.70</b>	<b>12.37**</b>	<b>0.64</b>	<b>119.50</b>
Worry of Recurrence	<b>.16</b>	<b>.05</b>	<b>.20</b>	<b>3.47*</b>		

Note. Significant statistics are bolded; \*\* $p < .001$ , \* $p < .05$

### *Depression*

Trait anxiety and chemotherapy treatment were included as covariates in the multiple regression analysis evaluating worry of a recurrence as a predictor of depression (see Table 5-7). Hormonal treatment and age were not included as covariates, as preliminary regression analysis revealed that they were non-significant. Chemotherapy treatment and trait anxiety explained 52.4% of the variance in depression at Step 1 of the analyses. After entry of worry of recurrence scores at Step 2, the total variance explained by the model was 53.6%  $F(3,133) = 51.2, p < .001$ . Overall trait anxiety and chemotherapy were found to be significant predictors of depression scores in participants, however contrary to prediction, worry of recurrence did not account for additional variance in depression scores,  $R^2$  change = 0.01,  $F$  change (1, 133) = 3.54,  $p > .05$ .

Table 5-7 Multiple Regression Analysis of Worry of Recurrence as a Predictor of Depression

	<i>B</i>	<i>SE B</i>	$\beta$	<i>T</i>	<i>R</i> <sup>2</sup>	<i>F</i>
Chemotherapy	<b>.84</b>	<b>.38</b>	<b>.14</b>	<b>2.20*</b>	<b>0.54</b>	<b>51.21</b>
Trait Anxiety	<b>.19</b>	<b>.02</b>	<b>.63</b>	<b>9.74**</b>		
Worry of Recurrence	.08	.04	.13	1.88		

Note. Significant statistics are bolded ; \* $p < .05$ , \*\* $p < .001$

### *Physical quality of life*

The ability of worry of recurrence to predict total physical quality of life scores after controlling for trait anxiety was evaluated (see Table 5-8). Treatment and age were not included as covariates due to their insignificant correlations with physical quality of life. Trait anxiety explained 16.4% of the variance in physical health scores at step 1, however, following addition of worry of cancer recurrence at step 2, the total variance explained by the model was 18.9 %,  $F(2, 125) = 14.55, p < .001$ . Overall, recurrence worry explained an additional 2.4% of the variance in physical quality of life scores after controlling for trait anxiety,  $R^2\text{change} = 0.02, F\text{ change}(1, 125) = 3.74, p < .05$ . Findings were consistent with the hypothesis that worry of recurrence is a significant predictor of physical quality of life, with higher levels of worry of recurrence predicting poorer physical quality of life.

Table 5-8 *Multiple Regression Analysis of Worry of Recurrence as a Predictor of Physical Quality of Life*

	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>	<i>R</i> <sup>2</sup>	<i>F</i>
Trait Anxiety	<b>-.40</b>	<b>.11</b>	<b>-.34</b>	<b>-3.82**</b>	<b>0.19</b>	<b>14.54</b>
Worry of Recurrence	<b>-.42</b>	<b>.22</b>	<b>-.17</b>	<b>-1.99*</b>		

*Note.* Significant statistics are bolded ;\*  $p < .05$ , \*\*  $p < .001$

### *Mental quality of life*

Trait anxiety was included as a covariate in the hierarchical multiple regression of worry of cancer recurrence as a predictor of mental quality of life (see Table 5-9). As treatment and age were insignificantly correlated with mental quality of life, these variables were removed from the analyses. Trait Anxiety was added at Step 1 of the regression model and explained 51.1% of the variance in mental quality of life scores. Entry of worry of recurrence at step 2, revealed that cancer worry did not significantly explain any additional variance in mental quality of life,  $R\text{ change} = 0.01, F\text{ change}(1, 132) = 2.72, p = .10$ . This

was contrary to the prediction of worry of recurrence being a significant predictor of mental quality of life.

*Table 5-9 Multiple Regression Analysis of Worry of Recurrence as a Predictor of Mental Quality of Life*

	<i>B</i>	<i>SE B</i>	$\beta$	<i>T</i>	<i>R</i> <sup>2</sup>	<i>F</i>
Trait Anxiety	<b>-.77</b>	<b>.08</b>	<b>-.67</b>	<b>-10.19**</b>	<b>52.1</b>	<b>71.82</b>
Worry of Recurrence	-.25	.15	-.11	-1.65		

*Note.* Significant statistics are bolded ;\*\* $p < .001$

#### **Section 4: Illness Representations as Predictors of Worry of Cancer Recurrence**

Hierarchical multiple regressions was used to assess which representational attributes uniquely predict worry of recurrence, after controlling for age, chemotherapy treatment, hormonal treatment and trait anxiety. As preliminary analyses revealed no correlation between personal control and cancer worry, and very high correlations between emotional representations and cancer worry, these variables were not included in the analyses. Age, chemotherapy treatment, hormonal treatment and trait anxiety were added at step 1, explaining 22.9% of the variance in worry of recurrence scores. Following inclusion of the illness representation and imagery subscales at step 2, age, chemotherapy treatment and trait anxiety became non-significant. The total variance explained by the model as a whole was 39.1%,  $F(11,107) = 6.25, p < .001$ .

The illness representation and imagery subscales explained an additional 16.2% of the variance in worry of recurrence,  $R^2$  change = 0.16,  $F$  change (7, 107) = 4.08,  $p < .001$ . Age, chemotherapy treatment, hormonal treatment, and trait anxiety were removed as covariates in the final regression analysis (see Table5-10). This analysis revealed that identity, acute/chronic timeline, and consequences independently predicted worry of cancer

recurrence scores. The other illness representation dimensions, including the creature-like image group did not account for any additional variance in recurrence worry.

Overall, the identity, acute/chronic timeline and consequences dimensions predicted worry of recurrence as predicted. However, the illness representation domains of cyclical timeline, personal control, treatment control, coherence and cancer image groups did not predict levels of worry of recurrence as hypothesised.

Table 5-10 *Multiple Regression Analysis of Illness Representations as Predictors of Worry of Cancer Recurrence*

	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>	<i>R</i> <sup>2</sup>	<i>F</i>
<i>Illness Representations</i>					.39	6.25*
Timeline	<b>1.37</b>	<b>.63</b>	<b>.22</b>	<b>2.18*</b>		
Consequences	<b>1.23</b>	<b>.51</b>	<b>.24</b>	<b>2.42*</b>		
Treatment Control	-0.78	.80	-.09	-.97		
Coherence	-0.19	.48	-.03	-.41		
Cyclical	0.22	.54	.04	.40		
Identity	<b>0.20</b>	<b>.10</b>	<b>.18</b>	<b>2.07*</b>		
Creature vs No Creature Image	0.14	.53	.03	.26		

*Note.* Significant statistics are bolded; \*  $p < .05$

## Section 5: Coping with Worry of Cancer Recurrence

### *Principal components analysis of the Coping with Worry of Recurrence Measure*

The Coping with Worry of Cancer Recurrence measure (see Appendix A2) was further validated in the current study by examining each of the subscales through factor analysis and tests of internal consistency. Outcomes of the current principal components analyses (see Table 5-11) were compared to those obtained from the pilot test of the Coping with Worry of Cancer Recurrence Measure (Chapter 3). Attention was also focused on

whether new items included in the current measure loaded as hypothesized onto relevant subscales. Prior to testing, preliminary analyses confirmed the suitability of each subscale for factor analysis. Significant Bartlett's Tests of Sphericity and Kaiser-Meyer-Olkin statistics of .5 and above were generated indicating the factorability of each correlation matrix.

With the exception of the problem solving subscale items, the items comprising each subscale loaded onto a single factor. For the problem solving subscale, two factors were extracted. The item, "I focus on thinking about it" loaded separately from the others onto the second factor. The item 'I check myself for lumps or other signs of cancer' did not load sufficiently onto either factor. Overall, the rewording of the item 'I check myself for symptoms or signs that the cancer has returned' following pilot testing did not improve factor loading as anticipated. Both items were deleted from the final subscale as internal consistency testing indicated that their elimination increased the internal reliability of the subscale.

The findings from the principal components analyses of the spirituality, suppression and optimistic thinking subscales mirrored those of the pilot tests, with high item loadings and acceptable to excellent internal subscale consistencies. All of the original items were therefore retained in the final subscales. For the expression subscale, all items had reasonable to high loadings except for 'I write about it' which had a low loading of 0.38. Following reliability analyses this item was deleted from the final subscale as  $\alpha$  decreased from acceptable to good levels of consistency when the item was removed from the analysis. As a consequence, the final expression subscale consisted of a total of five instead of the original six proposed items. It was also noted that the reworded item, 'I tell myself that I'm being silly and that I'm fine, healthy and strong' of the expression subscale had similar loadings and frequency of use by participants compared to the original item 'I reassure myself that I'm fine, healthy and strong' in the pilot study.

All four items of the healthy living subscale were retained in the final subscale due to high loadings of all items, including the two new items, 'I go for walks' and 'I try to get enough sleep'. The internal consistency of the final healthy living subscale was also higher than that obtained in the pilot study. Similarly, all three items of the distraction subscale were retained including the reworded item 'I distract myself by doing something else' and new item 'I turn my focus to other things'. All items loaded highly onto the single factor.

All items pertaining to the new subscale of humour were retained due to high factor loadings and a good internal consistency of 0.82. The humour subscale was composed of the original, 'I try to laugh it off' item and a further 2 new items, 'I make jokes about it' and 'I make fun of the situation.'

In relation to the new substances subscale, it was not possible to calculate internal consistency due to there being too few items. Both new items, 'I use alcohol or drugs to help me get through it' and 'I use alcohol or drugs to make me feel better' were retained in the final subscales and included in the final subscale scores.

The final Coping with Worry of Recurrence measure thus consisted of the following nine subscales: problem solving, distraction, optimistic thinking, spirituality, expression, suppression, humour coping, substances coping and healthy living. An additional four items were added to the subscale following the pilot study for further exploratory purposes and included 'I practice deep breathing exercises, yoga or meditation,' 'I comfort myself by eating food,' 'I look for more information about cancer or cancer recurrence,' and 'I go to a doctor or health care professional for an examination to make sure the cancer hasn't returned.' Descriptive analyses in current study indicated that the frequency of use of these strategies were comparable to that in the pilot study with participants reporting using each strategy 'almost never' to 'sometimes'.

Table 5-11 *Factor Analysis with Item Means (M), Standard Deviations (SD), Factor Loadings, Kaiser-Meyer-Olkin Statistics and Internal Reliability of each of the Coping Subscales of the Coping with Worry of Cancer Recurrence Measure.*

	<i>M</i>	<i>SD</i>	Factor Loadings	KMO	Internal Consistency
<i>Problem Solving</i>				.64	.69
I check myself for lumps or other signs of cancer*	2.60	0.94			
I focus on thinking about it*	1.42	0.58			
I think through the reasons why the cancer may or may not come back.	2.00	0.68	.72		
I think through what might happen if it does come back	2.11	0.76	.84		
I focus on coming up with a strategy of what to do	1.90	0.92	.81		
<i>Distraction</i>				.63	.69
I distract myself by doing something else	2.66	0.92	.85		
I try to ignore or push these thoughts out of my mind	2.83	0.85	.81		
I turn my focus to other things	3.12	0.72	.70		
<i>Optimistic Thinking</i>				.61	.70
I focus on the positive aspects of my experience with cancer	3.09	0.87	.67		
I tell myself that I'm being silly and that I'm fine, healthy and strong.	2.80	0.87	.87		
I tell myself that I can handle it if the cancer comes back	2.61	0.90	.82		
<i>Spirituality</i>				.86	.93
I pray	1.91	1.08	.88		
I ask others to pray for me	1.43	.86	.79		
I go to my place of worship (church, temple, etc)	1.57	1.04	.87		
I trust in god to help me cope	2.09	1.18	.88		
I focus on the spiritual aspects of my experience	2.02	1.03	.87		
I go to places where I can connect with my spirituality	1.80	1.00	.85		
<i>Expression</i>				.76	.81
I talk to a friend, partner or family member about it	1.96	0.89	.82		
I write about it*	1.32	0.64	.38		
I let others know how I feel	1.62	0.72	.82		

I seek physical affection such as hugs from my family, partner or friends	2.21	0.93	.66		
I ask for advice from my family, partner or friends	1.52	0.79	.86		
I seek out sympathy and understanding from others	1.39	0.67	.75		
<i>Suppression</i>				.62	.82
I keep it to myself	3.06	0.93	.88		
I hide those feelings from others	3.14	0.81	.94		
I smother my feelings	2.63	1.03	.78		
<i>Humour</i>				.66	.82
I try to laugh it off	1.94	0.99	.80		
I make jokes about it	1.62	0.82	.92		
I make fun of the situation	1.63	0.84	.87		
<i>Substances Coping</i>				.50	.82
I use alcohol or drugs to help me get through it	1.13	0.46	.92		
I use alcohol or drugs to make me feel better	1.19	0.48	.92		
<i>Healthy living</i>				.66	.76
I go for walks	2.28	0.88	.79		
I try to get enough sleep	2.84	0.86	.69		
I try to eat a healthier diet	2.92	0.79	.75		
I try to include exercise in my daily routine	2.86	0.86	.82		
<i>Additional Items</i>					
I practice deep breathing exercises, yoga or meditation	1.70	0.79			
I comfort myself by eating food	1.55	0.73			
I look for more information about cancer or cancer recurrence	1.79	0.88			
I go to a doctor or health care professional for an examination to make sure the cancer hasn't returned	2.38	1.14			

\* Did not load onto factor in the rotated component matrix ; Subscale items were rated from 1 (*Almost Never*) to 5 (*Almost Always*)

*Correlational analysis of the relationship between coping strategies and worry of recurrence at time 1 and time 2*

A preliminary analysis of the relationship between coping strategies and worry of recurrence at time 1 and 2 were assessed through correlational analyses. Inspection of the correlation coefficients indicated no significant associations between levels of worry of recurrence and the coping strategies of suppression, expression, humour, substances coping, healthy living and distraction. However significant correlations were revealed between worry of recurrence and the coping strategies of optimistic thinking, avoidance and problem solving across both time points; and spirituality at Time 2 (see Table 5-12).

Medium sized negative correlations between cancer worry and optimistic thinking at time 1 and 2, suggested that higher levels of optimistic thinking was associated with lower levels of worry of recurrence. Conversely, a medium sized positive correlation between cancer worry and problem solving indicated that higher levels of problem solving was linked to greater levels of worry of recurrence at both time points. For avoidance coping, greater use of avoidance at time 1 was associated with higher cancer worry concurrently and increases in worry of recurrence over the short term. Finally, while no association was found between levels of worry of recurrence and spiritual coping at time 1, a small negative correlation was indicated at time 2, suggesting that greater spiritual coping at time 1 was associated with a decrease in cancer worry over the short term. Overall, the directionality of the significant relationships between coping and worry of recurrence were as predicted, however, contrary to hypothesis correlational analysis revealed no relationship between worry of recurrence and other coping domains.

The relationships between worry of recurrence and coping strategies as highlighted through the current correlational analyses were further explored through multiple regression analyses. The purpose of the multiple regression was to evaluate which coping strategies

independently predict worry of recurrence concurrently and over time, while controlling for age, trait anxiety and cancer treatments.

Table 5-12. *Correlations between Coping Subscales of the Coping with Worry of Cancer Recurrence Measure and Levels of Cancer Worry at Time 1 and 2*

	FoR1	FoR2	Suppression	Expression	Spirituality	Optimistic Thinking	Humour	Substances Coping	Problem Solving	Healthy Living	Distraction	Avoidance
FoR 1	-											
FoR 2	<b>.78**</b>	-										
Suppression	.04	.05	-									
Expression	<b>-.28**</b>	<b>-.22*</b>	-.06	-								
Spirituality	-.11	<b>-.24*</b>	-.08	-.07	-							
Optimistic Thinking	<b>-.44**</b>	<b>-.38**</b>	.09	-.06	.10	-						
Humour	.01	.08	.11	.00	-.18	<b>.20*</b>	-					
Substances coping	.09	.16	.16	-.07	-.13	<b>-.20*</b>	-.13	-				
Problem Solving	<b>.38**</b>	<b>.39**</b>	.13	-.09	-.06	<b>-.21*</b>	<b>.23*</b>	.14	-			
Healthy Living	-.10	-.06	-.08	.05	-.10	<b>.22*</b>	-.06	-.02	-.04	-		
Distraction	.02	.05	<b>.37**</b>	-.14	-.02	<b>.38**</b>	.16	.07	.04	<b>.24**</b>	-	8
Avoidance	<b>.31**</b>	<b>.48**</b>	<b>.25**</b>	-.07	-.04	-.11	.12	<b>.29**</b>	<b>.26**</b>	.01	.18	-
<i>Mean</i>	8.52	7.62	2.94	1.67	1.81	2.83	1.73	1.16	2.00	2.73	2.87	.91
<i>S.D.</i>	4.87	4.94	.79	.56	.88	.69	.76	.43	.62	.65	.65	.82
<i>N</i>	143	138	118	117	106	118	117	118	119	117	118	138

*Note.* Significant statistics are bolded ; \*p< .05; \*\*p<.001

*Coping Strategies as predictors of worry of cancer recurrence*

*Coping as a predictor of concurrent worry of recurrence.* The avoidance subscale of the Impact of Events Scale Revised (IES-R) was included in this analysis as a coping strategy, as women identified using avoidance in their free responses, to cope with cancer worry. During the current analysis, age, trait anxiety, and treatment were removed as covariates, as preliminary analysis indicated that were insignificant (see Table 5-13). Thus a standard multiple regression was conducted. The analysis indicated that 43.1 % of the variance in worry of recurrence scores were explained by the coping variables ( $R^2 = 0.43$ ,  $p < .001$ ). Optimistic thinking ( $\beta = -.43$ ,  $p < .001$ ), avoidance ( $\beta = .26$ ,  $p < .05$ , expression ( $\beta = -.24$ ,  $p < .05$ ), and problem solving ( $\beta = .21$ ,  $p < .05$ ) were all statistically significant contributors to worry of recurrence scores concurrently. The other coping dimensions did not make a unique contribution to worry of recurrence. Overall, positive thinking made the strongest contribution to predicting worry of recurrence scores concurrently, explaining 13.4% of the variance in total worry of cancer recurrence scores at time 1. Avoidance, expression and problem solving accounted for 6.2%, 5.3% and 3.6% of the variance respectively.

Table 5-13 *Multiple Regression Analysis of Coping Strategies as Predictors of Concurrent Worry of Recurrence*

	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>	$R^2$	<i>F</i>
<i>Coping Subscales</i>					<b>0.43**</b>	<b>5.53**</b>
Suppression	-.32	.61	-.05	-.53		
Spirituality	-.51	.51	-.09	-1.0		
Positive Thinking	<b>-3.05</b>	<b>.73</b>	<b>-.43</b>	<b>-4.16**</b>		
Humour	-.01	.63	-.00	-.02		
Alcohol and Drugs	-.98	1.28	-.07	-.76		
Problem Solving	<b>1.68</b>	<b>.77</b>	<b>.21</b>	<b>2.19*</b>		
Healthy Living	-.17	.72	-.02	-.24		
Distraction	.88	.82	.12	1.08		
Expression	<b>-2.06</b>	<b>.79</b>	<b>-.24</b>	<b>-2.61*</b>		
Avoidance	<b>1.54</b>	<b>.56</b>	<b>.26</b>	<b>2.78*</b>		

Note. Significant statistics are bolded ; \* $p < .05$ , \*\* $p < .001$

*Coping as a predictor of worry of recurrence over a month.* The ability of coping strategies to predict worry of recurrence over the period of a month was evaluated using hierarchical multiple regression. Age and hormonal treatment were removed from the analysis as preliminary analysis indicated that they were nonsignificant covariates (see Table 5-14). As a consequence, chemotherapy and trait anxiety were added at Step 1 and explained 37.2% of the variance in worry of recurrence scores at time 2. After entry of all of the coping subscales including avoidance at Step 2, the total variance explained by the model as a whole was 62.6%  $F(12,71) = 9.91, p < .001$ . Overall, the coping subscales explained an additional 25.4% of the variance in worry of recurrence scores at time 2, after chemotherapy and trait anxiety were controlled for,  $R$  change = 0.25,  $F$  change (10,71) = 4.82,  $p < .001$ .

In the final model, chemotherapy ( $\beta = .20, p < .05$ ), trait anxiety ( $\beta = .22, p < .05$ ), spirituality ( $\beta = -.22, p < 0.05$ ), optimistic thinking ( $\beta = -.23, p < 0.05$ ), problem solving ( $\beta = .18, p < 0.05$ ), and avoidance ( $\beta = .36, p < 0.05$ ) were the only statistically significant contributors to worry of recurrence scores at time 2. Age, hormonal treatment and the other coping dimensions did not make a unique contribution to worry of recurrence scores at time 2. Overall, avoidance at time 1 made the strongest statistically significant contribution to predicting worry of recurrence scores at time 2, explaining 8.6% of the variance in worry of recurrence. Chemotherapy, trait anxiety, spirituality, optimistic thinking and problem solving explained 3.6%, 2.5% and 4.3% , 3.3% and 2.7% of the variance respectively when the variance explained by all the other variables were controlled for.

Overall, as predicted coping strategies of spirituality and optimistic thinking were associated with reductions in worry of recurrence while avoidance and problem solving were associated with higher levels of worry of recurrence. However, contrary to prediction other coping strategies of suppression, expression, distraction, substance coping, humour and healthy living were not significant predictors of worry of recurrence.

Table 5-14 Multiple Regression Analysis of Coping Strategies as Predictors of Worry of Recurrence One Month Later

	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>	<i>R</i> <sup>2</sup>	<i>F</i>
<i>Coping Subscales, Chemotherapy and Trait Anxiety</i>					<b>.63**</b>	<b>9.91**</b>
Chemotherapy	<b>1.99</b>	<b>.76</b>	<b>.20</b>	<b>2.63*</b>		
Trait Anxiety	<b>.11</b>	<b>.05</b>	<b>.22</b>	<b>2.19*</b>		
Suppression	-.77	.52	-.12	-1.48		
Expression	-1.22	.66	-.14	-1.83		
Spirituality	<b>-1.22</b>	<b>.43</b>	<b>-.22</b>	<b>-2.86*</b>		
Optimistic Thinking	<b>-1.67</b>	<b>.66</b>	<b>-.23</b>	<b>-2.53*</b>		
Humour	-.20	.54	-.03	-.37		
Substances coping	.58	1.09	.04	.54		
Problem Solving	<b>1.46</b>	<b>.65</b>	<b>.18</b>	<b>2.26*</b>		
Healthy Living	-.11	.61	-.01	-.18		
Distraction	1.01	.70	.13	1.44		
Avoidance	<b>2.15</b>	<b>.53</b>	<b>.36</b>	<b>4.05**</b>		

Note. Significant statistics are bolded; \* $p < 0.05$ , \*\* $p < 0.001$

*Coping as a predictor of changes in worry of recurrence.* The ability of coping strategies to predict change in worry of recurrence over the period of a month was evaluated using hierarchical multiple regression. Age and treatment were removed from the analysis as preliminary analysis indicated that they were not significant covariates (see Table 5-15). Worry of recurrence at time 1 and trait anxiety were added at Step 1 and explained 67.8% of the variance in worry of recurrence scores at time 2. After entry of all of the coping subscales including avoidance at Step 2, the total variance explained by the model as a whole was 76.0%,  $F(12,71) = 18.76$ ,  $p < .001$ . Overall, the coping subscales explained an additional 8.2% of the variance in worry of recurrence scores at time 2, after worry of recurrence scores at time 1 and trait anxiety were controlled for,  $R$  change = 0.08,  $F$  change (10,71) = 2.44,  $p < .001$ .

In the final model, worry of recurrence at time 1 ( $\beta = .55$ ,  $p < .001$ ), avoidance ( $\beta = .22$ ,  $p < .05$ ), trait Anxiety ( $\beta = .20$ ,  $p < .05$ ), and spirituality ( $\beta = -.17$ ,  $p < 0.05$ ) were the only

statistically significant contributors to changes in worry of recurrence scores over the short term. Age, treatment and the other coping dimensions did not make a unique contribution to changes in worry of recurrence scores at time 2.

Worry of recurrence at time 1 made the strongest statistically significant contribution to predicting change in worry of recurrence scores at time 2, explaining 17.1% of the variance in worry of recurrence at time 2. Avoidance, trait anxiety and spiritual coping explained 3.2%, 2.0% and 2.6% of the variance respectively when the variance explained by the other coping subscales, trait anxiety and worry of recurrence at time 1 were controlled for. Overall, as predicted the directionality of the relationship between avoidance and spiritual coping were in line with predictions.

*Table 5-15 Multiple Regression Analysis of Coping Strategies as Predictors of Worry of Recurrence One Month Later*

	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>	<i>R</i> <sup>2</sup>	<i>F</i>
<i>Coping Subscales and Trait Anxiety</i>					<b>0.76**</b>	<b>18.76**</b>
Worry of Recurrence Time 1	<b>.56</b>	<b>.08</b>	<b>.55</b>	<b>7.12**</b>		
Trait Anxiety	<b>.10</b>	<b>.04</b>	<b>.20</b>	<b>2.47*</b>		
Suppression	-.67	.41	-.12	-1.62		
Spirituality	<b>-.96</b>	<b>.35</b>	<b>-.17</b>	<b>-2.77*</b>		
Positive Thinking	-.21	.57	-.03	-.37		
Humour	-.02	.43	-.00	-.04		
Alcohol and Drugs	1.26	.87	.09	1.44		
Problem Solving	.62	.53	.08	1.16		
Healthy Living	-.13	.49	-.02	-.26		
Distraction	.67	.56	.09	1.19		
Expression	-.21	.55	-.02	-.37		
Avoidance	<b>1.35</b>	<b>.44</b>	<b>.22</b>	<b>3.09*</b>		

*Note.* Significant statistics are bolded; \* $p < 0.05$ , \*\* $p < 0.001$

## Section 6: Summary

Consistent with hypothesis 2, correlational analyses confirmed that higher levels of worry of recurrence were associated with younger age, chemotherapy, hormonal treatment and higher levels of trait anxiety. As a consequence of these findings, these variables were included in further examinations of the relationships between worry of recurrence and relevant constructs. However, regression analyses revealed that age and trait anxiety were the only significant predictors of worry of recurrence.

Preliminary correlational analyses was mostly consistent with hypothesis 3, revealing that higher levels of worry of recurrence was associated with poorer mental wellbeing (anxiety, depression and posttraumatic symptoms) and poorer functioning on most domains of quality of life, with the exception of the physical functioning where the relationship was nonsignificant. Outcomes of the multiple regression analyses of worry of recurrence as a predictor of anxiety, depression, physical quality of life and mental quality of life was mixed. Consistent with prediction, results indicated that worry of recurrence was a significant predictor of anxiety and physical quality of life, however contrary to expectation, worry of recurrence was not a predictor of depression and mental quality of life in women.

Correlational analyses revealed that the relationship between illness representation attributes including imagery and worry of recurrence were in line with hypothesis 4, with the exception of personal control for which no significant relationship was found. However, only illness representation attributes of identity, acute/chronic timeline and consequences were found to significantly predict worry of recurrence scores in the direction predicted. Contrary to prediction, the other illness representation domains including imagery groups, did not predict worry of recurrence.

Findings pertaining to hypothesis 5 were mixed. Relationships between worry of recurrence and coping strategies of avoidance, problem solving, optimistic thinking,

expression and spirituality were consistent with prediction. However no significant relationship between worry of recurrence and coping strategies of distraction, suppression, humour, substances coping and healthy living were uncovered. Multiple regression analyses revealed that optimistic thinking, avoidance, expression and problem solving predicted levels of concurrent worry of recurrence, in the direction hypothesized. Spirituality, optimistic thinking, problem solving and avoidance were also found to be predictive of worry of recurrence over a month, while avoidance and spirituality also predicted changes in worry of recurrence over time.

## CHAPTER VI: DISCUSSION

### Overview

Of the estimated 2500 women diagnosed with breast cancer in New Zealand (Ministry of Health, 2008), up to 90.0% will experience worries of cancer recurrence (Mast, 1998; Schover, Yetman, Tuason, Meisler, Esselstyn, Hermann, et al., 1995). However, despite the prevalence and persistence of worry of recurrence over time and its negative impacts on women's wellbeing, little is known about factors associated with women's worry. As such, the current study was focused on understanding these factors in the hopes that it would inform psychological treatments or informational material provided to women with breast cancer.

Relationships of interest in the current study included associations between women's worry of recurrence and time since cancer diagnosis, age, treatment type, trait anxiety and psychological wellbeing. In addition, there was an examination of the impact of women's illness perceptions and coping on levels of worry of recurrence. To aid in the understanding of women's coping, a new measure, Coping with Worry of Recurrence, was developed and validated to assess the impacts of various coping strategies on levels of recurrence worry, both concurrently and over the long term.

Several important findings emerged including associations of higher worry of recurrence with younger age, higher trait anxiety, and receiving chemotherapy and hormonal treatment. In relation to psychological wellbeing, preliminary analyses suggested that poor quality of life and poor psychological functioning, including higher levels of depression, anxiety and post traumatic symptoms were associated with greater worry of recurrence. Most importantly, while worry of recurrence did not predict depression or mental quality of life, it was found to predict anxiety and physical quality of life in women. Finally, the benefits of optimism, expression and spiritual coping were emphasised in the current investigation, while

strategies of avoidance and problem solving were found to negatively impact women's worry of recurrence. These relationships were independent of time since diagnosis, which was unrelated to worry of recurrence.

The findings of the current study, in relation to previous research are examined in this section. The current chapter is presented in six sections, beginning with an outline of the relationship of worry of recurrence with time since diagnosis, age, and treatment type. Section 2 describes findings pertaining to the relationship of worry of recurrence with mental wellbeing and quality of life. Section 3 presents associations between women's illness representations, including their mental image of breast cancer and worry of recurrence, and compares these findings with previous studies. Section 4 outlines findings relating to the newly developed Coping with Worry of Recurrence Measure and the impact of women's coping on worry of recurrence, both concurrently and over a month. Section 5 describes the implications, limitations and strengths of the current study, and finally, Section 6 provides an overall summary and conclusion.

### **Section 1. Associations between Time since Diagnosis, Age and Treatment Type on levels of Worry of Recurrence**

The current study uncovered no association between women's worry of cancer recurrence and time since diagnosis. This may suggest that women's levels of worry of recurrence following treatment are comparable to that three years post diagnosis. This finding was congruent with a previous investigation suggesting that worry of recurrence remains fairly stable over time (Leake et al., 2001).

Overall research pertaining to the relationship between women's age and their levels of worry of recurrence specifically was limited, with existing research being mixed. Thus far, studies exploring this link have suggested either no differences in level of worry of recurrence amongst women at different life stages (Cimprich et al., 2002) or higher levels of worry of recurrence in younger women compared to older women (Mast, 1998; Ziner et al.,

2012). The findings of the current research are consistent with previous findings indicating a relationship between younger age and worry of cancer recurrence (Mast, 1998; Ziner et al., 2012). It is likely that this finding is reflective of the hypothesis that younger women experience higher levels of worry of recurrence due to the impact of cancer on fulfilling roles and responsibilities relevant to their life stage (Ziner

et al., 2012), and worries relating to the impact of a future recurrence across all domains of their life (Vickberg, 2003). Given research indicating a strong link between worry of recurrence and psychological wellbeing, the current finding also appears to support previous research suggesting that worry of recurrence is likely to be high and may potentially contribute to greater psychological distress in younger women (Bloom et al., 2004; Ganz et al., 1998).

Prior research pertaining to the influence of adjuvant breast cancer treatment on worry of recurrence was scarce to non-existent. However, most research into women's general psychological adjustment post breast cancer treatment, has suggested poorer outcomes for women post chemotherapy (Amir & Ramati, 2002) and hormonal treatment (Ganz et al., 1996). As hypothesised, similar associations were found in the current study, with higher levels of worry of recurrence found for women who had undergone chemotherapy and hormonal treatment. A stronger association was found for chemotherapy in comparison with hormonal treatment, which is also consistent with research indicating strong associations between chemotherapy and poorer quality of life (Amir & Ramati, 2002; Mols et al., 2005).

It is likely that higher levels of worry of recurrence in women who had received chemotherapy was related to symptom experiences of early menopause, amenorrhea, hot flashes, fertility issues (Ganz et al., 1996), body image problems (Schover, Yetman, Tuason, Meisler, Esselstyn, & Hermann, 1995) and sexual difficulties (Knobf, 2006; Schover, Yetman, Tuason, Meisler, Esselstyn, & Hermann, 1995). Adverse symptoms may be

perceived as indications of a cancer recurrence, while for women several years post treatment, worry of recurrence may be exacerbated by lingering symptoms arising from past experiences of chemotherapy and associated impacts. Similarly, it is expected that higher levels of worry of recurrence following hormonal treatment may be related to symptoms of insomnia, weight gain, joint pain, fatigue, depression and hair loss vaginal problems, sexual difficulties, and hot flashes (Ganz, 2001; Ganz et al., 1996; Ganz et al., 2003). Research examining the impact of radiotherapy on worry of recurrence is non-existent. The current study found no association between worry of recurrence and radiotherapy which appeared consistent with recent findings on updated methods of radiotherapy, where no relationship between radiotherapy and quality of life was found (Lee et al., 2008).

Nevertheless, the observed associations between chemotherapy and worry of recurrence must be considered with caution, as multiple regression analyses indicated that the associations became nonsignificant when controlling for age and trait anxiety. These patterns of findings may indicate that the observed relationship may be due to younger women being both more likely to receive chemotherapy and experience worry of recurrence; the role of trait anxiety is unclear, although chemotherapy may exacerbate experiences of distress that are commonly associated with this personality trait. Further research examining the dynamics among chemotherapy experiences, age, and worry of recurrence is warranted to better understand the causal relationships.

## **Section 2. The relationship between Worry of Recurrence, Mental Wellbeing, and Quality of Life**

### *Anxiety, depression and post traumatic symptoms*

The present findings were consistent with the study hypothesis and previous research indicating a positive relationship between worry of recurrence and anxiety (Humphris et al., 2003), depression (Kim et al., 2012) and post traumatic symptoms (Mehnert et al., 2009). Findings also supported earlier research suggesting that worry of recurrence is a contributing

factor to poorer psychological adjustment and distress in breast cancer survivors (Ferrell et al., 1998; Fredette, 1995; Rowland, 1999). However, it could also be argued that experiences of anxiety and depression exacerbate worry of recurrence, accounting for the positive relationship between these variables.

The strong associations between worry of recurrence and intrusive thoughts, suggest that women's worry of recurrence are likely to manifest itself as intrusive memories or reminders of breast cancer or related symptoms. The positive relationship between worry of recurrence with avoidance and hyperarousal was also as expected, indicating that women are likely to be 'on edge' as a consequence of their worry, and hypervigilant to symptoms or cues suggestive of a recurrence, with avoidance representing efforts to circumvent reminders of breast cancer.

Regression analyses revealed that worry of recurrence was a predictor of anxiety but not depression in participants. This was in line with research suggesting a stronger impact of worry of recurrence on levels of anxiety over time (Humphris et al., 2003). Research has also suggested that worry of recurrence influences levels of depression during the early stages post treatment (Humphris et al., 2003); as most participants in the current study were two years post treatment on average, the association between worry of recurrence and depression may have dissipated by this point in the cancer experience.

Trait anxiety was the strongest predictor of both anxiety and depression in participants, explaining the greatest variability in scores, while age and hormonal treatment did not predict these aspects of mental wellbeing. Chemotherapy was also found to be a predictor of depression but not anxiety. Overall, findings were consistent with research indicating trait anxiety as a most significant predictor of distress in women with breast cancer and with benign breast problems (Lockfeer & De Vries, 2012). In relation to worry of

recurrence, it is also likely that women's predisposition for problems related to worry of recurrence are significantly influenced by trait anxiety.

### *Quality of Life*

Correlational analyses was consistent with research identifying associations between worry of recurrence and poorer quality of life in breast cancer survivors (Kim et al., 2012; Mellon et al., 2006).

In relation to the physical domain of quality of life, findings indicated no associations between worry of recurrence and women's ability to conduct everyday physical activities including running, lifting objects and climbing stairs, but a clear association between worry of recurrence and women's limited ability to fulfil physical roles including work or other activities (ie. accomplishing less, having difficulties performing work or having to cut down on time spent on work). Yet there was a positive relationship between pain and worry of recurrence, suggesting that women's experiences of pain may be being perceived as indications of a recurrence. Positive correlations between worry of recurrence and subscales of mental health indicated that worry of recurrence impacted women's ability to manage their roles, social interactions with others, vitality and mood.

It was slightly surprising to uncover correlations between general health and worry of recurrence that was comparable to that between worry of recurrence and total mental health. However, on inspection of items comprising the general health scale (ie. 'I expect my health to get worse'; 'My health is excellent; I am as healthy as anybody; and I seem to get sick a little easier than other people) this result may be explained given a logical link between worry of recurrence and item responses indicating negative appraisals of health status.

Overall, trait anxiety was the strongest predictor of both physical and mental quality of life, consistent with previous findings related to health and psychological aspects of quality of life following breast cancer (Weitzner et al., 1997). Worry of recurrence was found to be a

predictor of physical quality of life but not mental quality of life. The association between worry of recurrence and physical quality of life may be explained by symptoms and poor functioning being interpreted as indicators that the cancer may have returned or indications of being physical vulnerable to cancer. This suggests that worry of recurrence may be more closely tied to perceptions of physical health and functioning and not necessarily just a corollary of mental distress and depression.

In relation to mental quality of life, it is also possible that strong associations between worry of recurrence and trait anxiety, masks the impact of worry of recurrence as a predictor of mental quality of life. In addition, it was found that age and treatment were not predictors of physical and mental quality of life; with respect to treatment, it may be likely that trait anxiety influences women's psychological adaptation to treatment, thereby masking the influence of treatment on the relationship between worry of recurrence and quality of life.

### **Section 3. The relationship between Worry of Recurrence and Women's Illness Representations**

Correlational analyses indicated that the relationship between women's appraisals of breast cancer including cancer image groups and worry of recurrence were as hypothesised, with the exception of the personal control attribute of illness representations. More specifically, it was found that women with higher levels of worry of recurrence believed that their breast cancer was more unpredictable, chronic and had more severe consequences. They were also likely to have a 'creature like with intent' image of their cancer, be less likely to understand their breast cancer, more likely to experience a greater number symptoms they believed were indicative of a recurrence, experience poorer emotional responses to breast cancer, and have perceptions of treatment being less likely to control or cure their cancer. Results also highlighted a strong relationship between women's emotional responses to breast cancer and worry of recurrence providing further support for the impact of worry of recurrence on women's psychological wellbeing.

Overall, the current findings pertaining to each illness attribute were in line with previous studies; however, it is important to point out that few studies have examined the relationship between illness representations and worry of recurrence in breast cancer survivors specifically, so there are few points of comparison. As such, the findings of the current study are paralleled with investigations of the association between illness beliefs and worry of recurrence, or psychological wellbeing, in different illness populations.

In relation to the identity attribute of illness representations, current findings are in line with previous research indicating a positive association between symptom experiences and worry of recurrence (Campbell et al., 2000; Lee-Jones et al., 1997; Mellon et al., 2007; Skaali et al., 2009); this relationship may be attributed to symptoms being perceived as a cancer recurrence or serving as reminders of women's experiences of breast cancer.

With regards to consequences and emotional representation attributes, positive associations between representations of illness consequences and emotional representations, and worry of recurrence have also been demonstrated in a previous investigation of head and neck survivors (Llewellyn et al., 2008), providing further support for the potential impact of serious consequences beliefs on psychological wellbeing. Previous studies on the relationship between acute/chronic timeline beliefs and worry of recurrence have been mixed, however the findings of the current study supports outcomes indicating that more chronic timeline beliefs are associated with greater worry of recurrence (Lee-Jones, Humphris, Dixon, & Bebbington Hatcher, 1997; Rabin et al., 2004). It is likely that this relationship differs depending on the time since breast cancer diagnosis, and given that most women in the current study were approximately two years post diagnosis, it is likely that their chronic timeline beliefs reflect their perceptions of the cancer 'hiding' only to be discovered at some later time. It was noted that a previous study (Millar, Purushothamb, et al., 2005) finding an association between more acute timeline beliefs and higher worry of recurrence, investigated

this relationship in women in the year following cancer. It may be likely that at this early stage, when women are still adapting to their cancer diagnosis, beliefs of their cancer being swifter and more severe are perhaps stronger than over the long term, when beliefs are transformed to perceptions of the cancer being more insidious. Current findings also highlighted the link between a poorer understanding of breast cancer and greater worry of cancer recurrence, supporting previous findings highlighting the importance of disease coherence for psychological wellbeing (Mullins et al., 1995; Rabin et al., 2004) and lower recurrence worry (Skaali et al., 2009). While the current study found no associations between personal control and worry of recurrence, current findings supported previous findings emphasizing the importance of positive perceptions of the efficacy of treatment to control illness, on psychological wellbeing (Gould et al., 2010; Shapiro et al., 2001).

With respect to cancer imagery, the current investigation highlighted the association between women's 'creature like with intent' mental cancer image and higher levels of recurrence worry. In contrast, women's images of lumps or a benign cancer were found to be associated with lower levels of cancer worry. While there have been no quantitative evaluations of the relationship between breast cancer imagery and worry of recurrence, current findings appear to support a previous investigation by Harrow and colleagues (2008) indicating associations between 'parasitic creature like' breast cancer images and greater perceptions of threat and danger. Other similarities included the significance of the colour of cancer imagery, as it appeared that images signifying malevolent intent were often reported as being dark or black by participants in both studies. From further inspection of 'creature like with intent' imagery, it was also evident that many described their image as having "tentacles" or qualities of "spreading" or "crawling," suggesting associated beliefs of the cancer's ability to hide or spread to other parts of the breast or body. Overall, it was apparent

that women's cancer imagery could provide further valuable insight into illness beliefs and women's worry of cancer recurrence.

Variables of age, trait anxiety and treatment did not influence the relationship between women's beliefs and their level of worry of recurrence. However, perceptions of illness identity, acute/chronic timeline and to a slightly greater extent, consequences, were found to predict levels of worry of recurrence, thereby emphasizing the potential utility of these variables in identifying women who are more likely to experience psychological difficulties associated with worry of recurrence. Conversely, other illness attributes including having a 'creature like with intent' cancer image did not independently predict worry of recurrence. It is likely that the reciprocal relationship among attributes may 'mask' the ability of regression analyses to detect the contributions that respective variables make to women's worry of recurrence. For example, it may be likely that having a 'creature like with intent' cancer image prompts chronic timeline beliefs, stronger identity beliefs and more severe consequences beliefs, and these mediate the relationship between cancer imagery and worries of recurrence. Further research using mediational analyses to evaluate these relationships are warranted.

Results also provided further evidence for the reciprocal influence of the cognitive and emotional domains of the Common Sense Model of Self Regulation. This was indicated by a strong relationship between perceptions of a chronic disease course, severe consequences, lower treatment control and poorer coherence with negative emotional responses to breast cancer. Furthermore, findings also supported the concept of illness coherence (Cameron & Moss-Morris, 2010; Moss-Morris et al., 2002), with a more chronic timeline, more severe consequences, greater number of symptoms, poorer emotional responses and an unpredictable disease course being associated with beliefs of lower treatment control and coherence.

#### **Section 4. Coping with Worry of Cancer Recurrence**

This study included the design and validation of the new Coping with Worry of Cancer Recurrence Measure. The final Coping with Worry of Recurrence measure contains 36 items, including four exploratory items and the following nine subscales: problem solving, distraction, optimistic thinking, spirituality, expression, suppression, humour coping, substances coping and healthy living. Statistical testing indicated adequate convergent and discriminant validity, however while most of the subscales of the new measure revealed acceptable to excellent levels of internal consistency, the internal consistency of the distraction and problem solving subscales were questionable. Future investigations are encouraged to further explore the psychometric properties of the measure and adapt it to suit populations of interest.

Contrary to the hypothesis, preliminary correlational analyses indicated no association between coping strategies of suppression, expression, humour, substances coping, healthy living and distraction; and levels of worry of recurrence either concurrently or over time. This was in contrast to studies indicating the benefits of humour (Carver et al., 1993; Johnson, 2002) and the negative impacts of suppression (Watson et al., 1991) on psychological wellbeing. It is important to emphasise that it was difficult to compare outcomes pertaining to these coping strategies for which no relationship with worry of recurrence was uncovered, given there have been no studies evaluating the impact of these coping strategies on worry of recurrence in breast cancer survivors specifically.

As predicted findings indicated that optimistic thinking was related to lower levels of recurrence, while spirituality was linked to improvements in worry of recurrence over a month. Also, as expected, avoidance and problems solving were associated with higher levels of worry of recurrence across both time points. With regards to problem solving, this was consistent with previous research (Mehnert et al., 2009). On inspection of the items

comprising the subscale, both explanations provided by Mehnert and colleagues (2009) appear plausible, including women turning to problem solving because of significant worry of recurrence, or women with a greater worry of the future consequences of a recurrence, being more likely to turn to problem solving. However, an additional explanation for findings in the current study might be attributed to the item composition of the problem solving subscale, also reflecting women's rumination about a cancer recurrence.

While studies on the efficacy of avoidance coping have been mixed, the current investigation of participants up to three years post diagnosis is concordant with the findings of a study by Stanton and colleagues (2002), indicating higher levels of worry of recurrence in women over the longer term. This appears to support the theory of avoidance strategies compromising women's ability to be more proactive and to make positive decisions to attend to their concerns (Stanton & Snider, 1993).

Multiple regression analyses highlighted the ability of coping strategies of expression, optimistic thinking, problem solving, spirituality and avoidance in predicting worry of recurrence in survivors of breast cancer. In contrast to the preliminary analyses of expression coping, expression coping was found to predict lower levels of concurrent worry of recurrence, suggesting some benefit for women using this strategy to manage their immediate worries of recurrence. This was in line with previous research suggesting a positive relationship between expression coping and psychological wellbeing (Goodwin et al., 2001; Moyer & Salovey, 1996; Spiegel, 1997; Stanton et al., 2002). On inspection of items comprising the subscale, it is also likely that the mobilisation of social support that expression elicits, aided in positive outcomes.

Women's use of problem solving and avoidance coping were associated with high levels of worry of recurrence concurrently and over time further emphasizing the negative impacts of these coping strategies on women's worry. In support of previous findings in

breast cancer survivors (Stanton et al., 2002), optimistic thinking was found to be a useful strategy for managing worry of recurrence both concurrently and over the short term. As has been pointed out previously, this may be related to women who are more optimistic being more proactive in dealing with their concerns and having more positive perceptions of their own and their treatment's ability to control cancer (Stanton et al., 2002). With regards to spirituality, while no benefits were evident for women using spiritual coping concurrently, this strategy appeared to predict improvements in worry of recurrence over the short term, emphasizing positive benefits for women. While previous research of the relationship between spirituality and worry of recurrence is mixed, current findings are in line with previous research suggesting the utility of spiritual coping for breast cancer survivors (Cameron et al., 2005), and it is likely that this association is due to the sense of control and hope women experience by turning to religion (Tix & Frazier, 1998).

Findings also indicated that higher trait anxiety and undergoing chemotherapy predicted increases in levels of worry of recurrence over time, with trait anxiety having the most significant negative impact on worry of recurrence over and above women's coping. Furthermore, the current study found that women's age and receiving hormonal treatment did not influence the relationship between coping strategies and levels of worry of recurrence.

## **Section 5. Implications and Future Directions, Limitations and Strengths**

### ***Implications and future directions***

Given the prevalence and enduring quality of worry of recurrence in breast cancer survivors and its impact on women's psychological wellbeing, there is a need for tailored and improved care to address women's worry of recurrence. Knowledge of the factors associated with worry of recurrence may be crucial if medical professional and nurses are to recognise particular types of patients that may be at risk of experiencing difficulties with worry of recurrence, so they may refer or attend to their concerns earlier and more adequately.

Furthermore, recognition of factors associated with worry of recurrence may be beneficial for mental health professionals in their design and implementation of therapy aimed at reducing worry of recurrence and improving psychological adjustment in with women with breast cancer.

Given findings suggesting higher levels of worry of recurrence in younger breast cancer survivors, it may be important for mental health professionals to be aware of and explore how women's worry of recurrence is related to adjustment difficulties associated with maintaining roles and responsibilities reflective of their life stage. A better understanding of worry of recurrence across difference life phases or age groups is also warranted given that only a single study by Cimprich and colleagues (2002) has examined this link. Furthermore, a qualitative evaluation of the content of women's worry of recurrence at each life stage would be beneficial for the design of interventions to address these particular concerns.

In relation to treatment, the current study indicated higher levels of worry of recurrence for women who had received chemotherapy or hormonal therapy. Chemotherapy was also found to be a significant predictor of depression in participants. Overall, these findings warrant the need for medical professionals to provide more comprehensive information about the risks, benefits and symptoms associated with each treatment. This may help women make more informed decisions about their treatment and help them develop a better understanding of what to expect. The normalising of symptom experiences may also circumvent problems relating to women's uncertainty of whether symptoms reflect a cancer recurrence. It is also important to point out that women have cited worrying about a future recurrence because of past experiences with chemotherapy (Vickberg, 2003); affirming the need for more support for women in coping with both the physical and psychological impacts of chemotherapy including body image problems, sexual problems and physical difficulties. In particular given that worry of recurrence was a predictor of physical quality of life, women

may benefit from clinical strategies that help them to reinterpret their symptoms, pain and poor functioning as not necessarily indicative of cancer recurrence. Furthermore, future research examining the relationship between treatment symptoms and levels of worry of recurrence could be helpful in extending our understanding of how specific symptoms contribute to women's worry of cancer recurrence.

Outcomes also suggest that medical and mental professionals need to be aware of the higher risk for poor adjustment across both physical and mental domains for women with a tendency to be anxious. In addition, given current findings of worry of recurrence as a significant predictor of anxiety, early intervention in the form of psychological treatment aimed at alleviating worry of recurrence is likely to reduce anxiety over the long term. It is also important to point out that the normalising of worry of recurrence post treatment by medical professionals may be beneficial in circumventing distress. Future studies investigating the impact of treatment of worry of recurrence should also examine the impacts of such treatment on anxiety over the long term, to provide further support of the importance of such treatment in achieving more positive psychological outcomes in women.

Given associations between posttraumatic symptoms and worry of recurrence in the current research, it is suggested that interventions targeting worry of recurrence incorporate strategies for alleviating related symptoms of intrusions, hyperarousal and avoidance. In addition, as the current study did not examine worry of recurrence as a predictor of changes in post traumatic symptoms over time, it may also be useful for future research to investigate this link.

Explorations of women's illness beliefs have emphasized the importance of exploring and further understanding women's perceptions of their breast cancer, given its potential impact on women's worry of recurrence and psychological wellbeing. This appears especially relevant to beliefs of more chronic timeline, severe consequences and symptom experiences,

which were found to predict women's worry of recurrence. As has been emphasised earlier, it is likely that more detailed information by medical professionals will improve women's coherence of breast cancer, and circumvent the impacts of persistent negative illness beliefs on psychological adjustment. More specifically, it is recommended that discussions with women include information about the expected course of their disease, common symptoms in breast cancer survivors, and the efficacy and side effects of treatment. With regards to cancer imagery, a previous study found that women's cancer imagery was influenced by discussions with medical professionals including mammograms, metaphors and drawings used by doctors (Harrow et al., 2008). Given the relationship between cancer images and worry of recurrence highlighted in the current study, it may also be important for medical professionals to be more aware of how these aspects of communication influence worry.

Furthermore, in relation to illness beliefs, the findings of the current study emphasize the need for mental health professionals to understand and explore the contents of women's illness beliefs and cancer imagery as described by the Self Regulation Model, with the overall goal of replacing negative illness perceptions with more helpful ones. With regards to further research, given that illness representations including personal and treatment control, coherence and cyclical timeline did not predict worry of recurrence, it may be useful for future investigations to explore the mediational effects of illness representations including cancer imagery on the relationship between respective illness attributes and worry of recurrence.

It is anticipated that the development of the new Coping with Worry of Cancer Recurrence scale would be beneficial to future research exploring the impact of coping on levels of worry of recurrence, in various cancer survivor populations. The current study also emphasised the benefits of coping strategies including optimism, spirituality and expression on alleviating worry of recurrence, while also highlighting the negative impacts of avoidance

and problem solving strategies. Given the impact of these strategies on women's worry of recurrence, it may be important for psychological interventions to assess women's coping with worry of recurrence and encourage strategies of optimism, expression, and spirituality, and discourage avoidance and problem focused coping. It is suggested that the new coping measure, in combination with the IES-R to evaluate avoidance, may be useful in clinical practise to assess coping in breast cancer survivors and for informing psychological treatment in this population.

### ***Limitations***

*Generalizability.* A significant limitation of the current study is the generalizability of findings to breast cancer survivors of different ethnic groups given that participants were predominantly of New European descent. As such, further investigation is recommended to replicate these findings with a sample representative of different ethnic groups. Also, given the questionnaire structure of the current study excluded potential participants who were not fluent in English, further study may benefit from the use of interpreters to support in the recruitment process.

Given the exclusion of participants undergoing treatment for psychological disorders it may be difficult to generalize findings of the current study to women with more extreme levels of distress.

*Self response format and response rate.* The questionnaire self response format is likely to have been subject to social desirability responses leading to lower reports of worry of recurrence and symptoms of depression, and anxiety. It is also possible that women with higher worry of recurrence and strategies of avoidance may have been less likely to have completed the surveys due to discomfort arising from confronting their experiences and worry of cancer recurrence. However, on inspection of worry of recurrence scores, there are a number of women reporting extremely high levels of worry indicating that this limitation

wasn't that severe. Also, the effects of social desirability are likely to have been reduced given the anonymity of the questionnaire and women being able to complete the questionnaire at their own pace, and in their own homes. However, future investigations may implement a different method of recruitment via breast cancer clinics and face to face interviewing to ascertain if findings can be extrapolated to women with higher levels of worry of recurrence. A shorter questionnaire, face to face recruitment and better follow up subsequent to sending questionnaires to prospective participants, may also improve the response rate of the current study of 35.0%. However, given the nature of the current study assessing women's worry of recurrence, it was deemed important that women who chose to participate were prepared to share their experiences and confront their worry of recurrence.

*Cancer staging.* The current study also did not include an examination of the impact of women's cancer staging on worry of recurrence based on the fact that all women were in remission and research indicating that most women with breast cancer are unaware of their cancer staging (Rabin et al., 2004). Instead, women are likely to rely on their treatment experiences (e.g., whether they required chemotherapy), symptom experiences, and beliefs about the timeline and controllability of cancer to determine their potential for cancer recurrence and spread. However, it may be argued that cancer staging impacts women's experiences of breast cancer particularly through symptom experiences, which in turn influence worry of recurrence. As such, it is recommended that further investigation of women's worry of recurrence includes an examination of the influence of cancer staging.

*Longitudinal design.* The current study was the first to investigate coping efforts directed at worry of recurrence on levels of worry of recurrence concurrently and over the short term. This was due to the aim of the current research, to understand the short term dynamics between coping and worry of recurrence. It was also on the premise that coping is dynamic, changing over time. Yet, while the current investigation was longitudinal, women

were followed over a short period of only one month. Therefore, little is known about women's coping over the longer term. Overall, it is suggested that the current study is replicated, with studies evaluating the relationships of coping strategies with worry of recurrence using alternative methodologies such as ecological momentary analyses or mixed model analyses, to evaluate weekly or monthly changes over a longer course of time, as self-regulation dynamics are likely have short time cycles.

*Type I error.* The likelihood of Type one errors is increased due to the high number of tests conducted for relationships between worry of recurrence and relevant constructs. Although the analyses yielded coherent patterns of findings, which suggests that the patterns were not simply due to Type 1 errors, further studies using larger samples should conduct refined sets of analyses with stricter controls of Type 1 error.

*Measures.* While most of measures used in the current study including the IPQ-R, IES-R, SF-36 and Spielberger's trait anxiety measure have been validated and used with various populations, the use of McCaul's brief worry measure has been used less frequently. However, it has been selected as the measure of choice, with versions used successfully in other studies of worry over recent years (Cameron et al., 2007; McCaul, 2003; Sandgren, Mullens, Erickson, Romanek, & McCaul, 2004). Furthermore, given its short, easy to administer format as compared to the CARS (Vickberg, 2003), for example, which is a 30 item measure of worry of recurrence, it was deemed to be the most appropriate measure of worry of recurrence in the current study. Recently, the Hospital Anxiety and Depression measure (HADS) has come under scrutiny for its response format and factor structure (Coyne & van Sonderen, 2012), with the authors dissuading its use as a measure of anxiety and depression. As such it is recommended that further studies take into account the points raised by the authors before implementing the HADS in future research. Finally, with regards to the newly developed 'Coping with Worry of Cancer Recurrence Measure, further study of its

psychometric qualities in cancer survivors is required to further validate its utility as a coping measure.

### ***Strengths***

*Self report format, sample size and completion rate.* The samples size of the current study of 143 is considered a strength; it is higher than the 130 participants recommended to detect differences if they existed. The completion rate of 97.9% in the current study suggested high retention of participants. The questionnaire format and use of codenames provided women with some degree of anonymity, likely reducing issues pertaining to social desirability which are likely to have been more significant via face to face interviewing. Women were also free to complete the questionnaire in their own time and in their own homes, and given the nature of the study, this was likely to be of some comfort to participants.

*Clinical applicability.* The findings of the current study particularly pertaining to the influence of illness beliefs, cancer imagery and coping strategies on women's worry of recurrence has practical applications including informing clinical treatment, information materials and communication by medical professionals. More specifically, unhelpful illness beliefs, creature like imagery and coping strategies that have been highlighted in the current study as predicting worry of recurrence, may be assessed and amended, producing better outcomes in women with breast cancer.

*Use of the cancer registry.* The use of the cancer registry provided access to the full population of female cancer survivors meeting the inclusion and exclusion criteria.

*Understanding women's illness beliefs and images.* Given the prevalence of worry of recurrence, one of the strengths of the current study was its exploration of how women perceive their illness and how this influences their cancer worry.

*New coping measure.* One of most significant strengths of the current investigation was the design of the new ‘Coping with Worry of Cancer Recurrence Measure’ because of its specific role to measure coping elicited at reducing cancer worry. Moreover, it was used in the current study to further our understanding of how women’s coping impacts their worry of cancer recurrence concurrently and over the short term. It is anticipated that this may be used in psychological treatment as a means of assessing women’s coping and identifying targets for treatment. Treatment may be guided by the findings of the current study on the impacts of various coping strategies on worry of recurrence. It may also be amended for use in future investigations of coping with worry of recurrence in various cancer populations.

## **Section 6. Summary and Conclusion**

The current study provides support for the importance of recognizing the role of women’s worry of recurrence on psychological wellbeing, particularly as a predictor of anxiety in women up to three years post diagnosis. To circumvent or attend to women’s worry of recurrence, findings emphasize the need for improved breast cancer coherence, particularly relating to women’s understanding of their treatments, symptom experiences and illness course. Women who may require earlier and greater intervention were also identified, including women of younger age, those receiving chemotherapy or hormonal treatment, and women with a predisposition for anxiety. Furthermore, the use of the self regulation model in the current study provided further evidence for the likely utility of the model in understanding the interaction between illness beliefs and worry of recurrence, in other cancer populations.

With regards to psychological treatment, findings suggest that clinicians need to be aware of the interaction between women’s illness perceptions, coping and emotional responses. It is suggested that an in-depth assessment of these factors is conducted, with findings of the current study and the new coping with recurrence measure informing targets for intervention. In addition, it is hoped that the new coping with worry of recurrence measure will stimulate further research into worry of cancer recurrence in other cancers.

Studies adopting the new measure are likely to provide greater insights into how coping elicited at managing worry of recurrence, impacts distress.

Overall, outcomes of the current study has implications, not only for interventions aimed at reducing worry of recurrence, but also for those targeting women's overall psychological wellbeing following breast cancer.

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**APPENDICES**

- A: Study Measures
1. Coping with Worry of Cancer Recurrence Measure (Pilot Study)
  2. Coping with Worry of Recurrence Measure (Revised)
  3. Demographics Assessment for Pilot Study
  4. Demographics Assessment for Main Study
  5. McCaul's Brief Worry Measure
  6. Hospital Anxiety and Depression Scale
  7. The Impact of Events Scale
  8. Spielberger Trait Anxiety Scale
  9. Mental Imagery Subscale of the Assessment of Illness Representations Revised
  10. Short Form 36 Quality of Life Measure
  11. Illness Perceptions Questionnaire Revised
- B: Pilot Study Consent Form
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- D: Main Study Consent Form
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## Appendix A1

### Coping with Worry of Cancer Recurrence Measure (Pilot Study)

Now we would like to learn more about how you cope with any worries you may have about your cancer returning. There are many different ways women deal with these concerns. For the purposes of this questionnaire please indicate what you generally do and feel, when you experience worry. Please respond to each question by circling the response that best applies to you. Remember that there are no right or wrong answers so please choose the response that best fits what YOU do.

When I feel worried about the cancer returning .....

	<b>Almost Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
I think through the reasons why the cancer may or may not come back.	1	2	3	4
I think through what might happen if it does come back	1	2	3	4
I check myself for symptoms or signs that the cancer has returned	1	2	3	4
I focus on coming up with a strategy of what to do	1	2	3	4
I distract myself by doing something else (work or other activities)	1	2	3	4
I try to ignore or push these thoughts out of my mind	1	2	3	4
I focus on the positive aspects of my experience with cancer	1	2	3	4
I reassure myself that I'm fine, healthy and strong	1	2	3	4
I tell myself that I can handle it if the cancer comes back	1	2	3	4
I pray	1	2	3	4
I ask others to pray for me	1	2	3	4

I go to my place of worship (church, temple, etc.)	1	2	3	4
I trust in God to help me cope	1	2	3	4
I focus on the spiritual aspects of my experience	1	2	3	4
I go to places where I can connect with my spirituality	1	2	3	4
I talk to a friend, partner or family member about it	1	2	3	4
I write about it	1	2	3	4
I let others know how I feel	1	2	3	4
I seek physical affection such as hugs from my family, partner or friends	1	2	3	4
I ask for advice from my family, partner or friends	1	2	3	4
I seek out sympathy and understanding from others	1	2	3	4
I keep it to myself	1	2	3	4
I hide those feelings from others	1	2	3	4
I smother my feelings	1	2	3	4
I try to eat a healthier diet	1	2	3	4
I try to include exercise in my daily routine	1	2	3	4
I do things that help me relax, such as deep breathing, yoga, etc.	1	2	3	4
I look for more information about cancer or cancer recurrence	1	2	3	4
I try to laugh it off	1	2	3	4
I use alcohol or drugs to help me cope	1	2	3	4
I comfort myself by eating food	1	2	3	4
I visit my doctor	1	2	3	4

## Appendix A2

### Coping with Worry of Recurrence Measure (Revised)

Now we would like to learn more about how you cope with any worries you may have about your cancer returning. There are many different ways women deal with these concerns. For the purposes of this questionnaire please indicate what you generally do and feel, when you experience worry. Please respond to each question by circling the response that best applies to you. Remember that there are no right or wrong answers so please choose the response that best fits what YOU do.

When I feel worried about the cancer returning .....

	<b>Almost Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
I check myself for lumps or other signs of cancer	1	2	3	4
I focus on thinking about it	1	2	3	4
I think through the reasons why the cancer may or may not come back.	1	2	3	4
I think through what might happen if it does come back	1	2	3	4
I focus on coming up with a strategy of what to do	1	2	3	4
I distract myself by doing something	1	2	3	4
I try to ignore or push these thoughts out of my mind	1	2	3	4
I turn my focus to other things	1	2	3	4
I focus on the positive aspects of my experience with cancer	1	2	3	4
I tell myself that I'm being silly and that I'm fine, healthy and strong.	1	2	3	4
I tell myself that I can handle it if the cancer comes back	1	2	3	4
I pray	1	2	3	4

I ask others to pray for me	1	2	3	4
I go to my place of worship (church, temple. etc)	1	2	3	4
I trust in god to help me cope	1	2	3	4
I focus on the spiritual aspects of my experience	1	2	3	4
I go to places where I can connect with my spirituality	1	2	3	4
I talk to a friend, partner or family member about it	1	2	3	4
I write about it	1	2	3	4
I let others know how I feel	1	2	3	4
I seek physical affection such as hugs from my family, partner or friends	1	2	3	4
I ask for advice from my family, partner or friends	1	2	3	4
I seek out sympathy and understanding from others	1	2	3	4
I keep it to myself	1	2	3	4
I hide those feelings from others	1	2	3	4
I smother my feelings	1	2	3	4
I go for walks	1	2	3	4
I try to get enough sleep	1	2	3	4
I try to eat a healthier diet	1	2	3	4
I try to include exercise in my daily routine	1	2	3	4
I try to laugh it off	1	2	3	4
I make jokes about it	1	2	3	4
I make fun of the situation	1	2	3	4
I use alcohol or drugs to help me get through it	1	2	3	4

I use alcohol or drugs to make me feel better	1	2	3	4
I practise deep breathing exercises, yoga or meditation	1	2	3	4
I comfort myself by eating food	1	2	3	4
I look for more information about cancer or cancer recurrence	1	2	3	4
I go to a doctor or health care professional for an examination to make sure the cancer hasn't returned	1	2	3	4

### Appendix A3 Demographics Assessment for Pilot Study

Your age: \_\_\_\_\_

Your Ethnicity: Note that ethnicity refers to your cultural identity, not your citizenship or birthplace. Please indicate the ethnicity you primarily identify with:

- NZ Maori
- NZ European / Pakeha
- Pasifika
- Asian
- Indian
- Other: \_\_\_\_\_

Occupation: \_\_\_\_\_

What is your highest educational level/qualification?

- Year 9
- Year 10
- NCEA Level 1
- NCEA Level 2
- NCEA Level 3
- Trade Certificate
- National Certificate or Diploma
- Bachelor's Degree
- Master Degree or PhD
- Other : \_\_\_\_\_

What is your marital status?

- Married
- Single
- Living with partner
- Divorced
- Widowed
- Separated

Do you have children?

- Yes                    If Yes, how many? \_\_\_\_\_
- No

Please indicate which category best describes the total income that you (and all other members in your household) earned in 2009 before taxes:

- Less than \$20,000
- \$20,001 - \$40,000
- \$40,001 - \$60,000
- \$60,001 - \$80,000
- \$80,001 - \$100,000
- \$101,000 or above

## Appendix A4 Demographics Assessment for Main Study

Your age: \_\_\_\_\_

Your Ethnicity: Note that ethnicity refers to your cultural identity, not your citizenship or birthplace. Please indicate the ethnicity you primarily identify with:

- NZ Maori
- NZ European / Pakeha
- Pasifika
- Asian
- Indian
- Other: \_\_\_\_\_

Occupation: \_\_\_\_\_

What is your highest educational level/qualification?

- Year 9
- Year 10
- NCEA Level 1
- NCEA Level 2
- NCEA Level 3
- Trade Certificate
- National Certificate or Diploma
- Bachelor's Degree
- Post Graduate Diploma
- Master Degree/ Doctorate or PhD
- Other : \_\_\_\_\_

What is your marital status?

- Married
- Single
- Living with partner
- Divorced
- Widowed
- Separated

Do you have children?

- Yes                      If Yes, how many? \_\_\_\_\_
- No

Please indicate which category best describes the total income that you (and all other members in your household) earned in 2010 before taxes:

- Less than \$20,000
- \$20,001 - \$40,000
- \$40,001 - \$60,000
- \$60,001 - \$80,000
- \$80,001 - \$100,000
- \$101,000 or above



## Appendix A6 Hospital Anxiety and Depression Scale

This section will help us understand how you have been feeling lately. Read every sentence and tick the box that best describes how you have been feeling in the LAST WEEK in general. Try not to think too much about each answer. For these questions, spontaneous answers are more important.

1. I feel tense or 'wound up':
  - Most of the time
  - A lot of the time
  - From time to time (occ.)
  - Not at all
  
2. I still enjoy the things I used to enjoy:
  - Definitely as much
  - Not quite as much
  - Only a little
  - Hardly at all
  
3. I get a sort of frightened feeling as if something awful is about to happen:
  - Very definitely and quite badly
  - Yes, but not too badly
  - A little, but it doesn't worry me
  - Not at all
  
4. I can laugh and see the funny side of things:
  - As much as I always could
  - Not quite so much now
  - Definitely not so much now
  - Not at all
  
5. Worrying thoughts go through my mind:
  - A great deal of the time
  - A lot of the time
  - From time to time, but not often
  - Only occasionally
  
6. I feel cheerful:
  - Not at all
  - Not often
  - Sometimes
  - Most of the time

7. I can sit at ease and feel relaxed:
- Definitely
  - Usually
  - Not often
  - Not at all
8. I feel as if I am slowed down:
- Nearly all the time
  - Very often
  - Sometimes
  - Not at all
9. I get a sort of frightened feeling like "butterflies" in the stomach:
- Not at all
  - Occasionally
  - Quite often
  - Very often
10. I have lost interest in my appearance:
- Definitely
  - I don't take as much care as I should
  - I may not take quite as much care
  - I take just as much care
11. I feel restless as I have to be on the move:
- Very much indeed
  - Quite a lot
  - Not very much
  - Not at all
12. I look forward with enjoyment to things:
- As much as I ever did
  - Rather less than I used to
  - Definitely less than I used to
  - Hardly at all
13. I get sudden feelings of panic:
- Very often indeed
  - Quite often
  - Not very often
  - Not at all
14. I can enjoy a good book or radio/TV program:
- Often
  - Sometimes
  - Not often
  - Very seldom

### Appendix A7 The Impact of Events Scale

Many women experience difficulties relating to the possibility of the cancer returning. Please read each item, and then indicate how distressing each difficulty has been for you during the past 7 days, by ticking the appropriate box. How much were you distressed or bothered by these difficulties?

		<b>Not at All</b>	<b>A Little Bit</b>	<b>Moderately</b>	<b>Quite a Bit</b>	<b>Extremely</b>
1.	Any reminder brought back feelings about it.	0	1	2	3	4
2.	I had trouble staying asleep.	0	1	2	3	4
3.	Other things kept making me think about it.	0	1	2	3	4
4.	I felt irritable and angry.	0	1	2	3	4
5.	I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	2	3	4
6.	I thought about it when I didn't mean to.	0	1	2	3	4
7.	I felt as if it hadn't happened or wasn't real.	0	1	2	3	4
8.	I stayed away from reminders about it.	0	1	2	3	4
9.	Pictures about it popped into my mind.	0	1	2	3	4
10.	I was jumpy and easily startled.	0	1	2	3	4
11.	I tried not to think about it.	0	1	2	3	4
12.	I was aware that I still had a lot of feelings about it, but I didn't deal with them.	0	1	2	3	4
13.	My feelings about it were kind of numb.	0	1	2	3	4

14.	I found myself acting or feeling like I was back at that time.	0	1	2	3	4
15.	I had trouble falling asleep.	0	1	2	3	4
16.	I had waves of strong feelings about it.	0	1	2	3	4
17.	I tried to remove it from my memory.	0	1	2	3	4
18.	I had trouble concentrating.	0	1	2	3	4
19.	Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.	0	1	2	3	4
20.	I had dreams about it.	0	1	2	3	4
21.	I felt watchful and on guard.	0	1	2	3	4
22.	I tried not to talk about it.	0	1	2	3	4

## Appendix A8 Spielberger Trait Anxiety Scale

A number of statements which people have used to describe themselves are given below. Read each statement and then tick the appropriate response to indicate how you generally feel. There are no right or wrong answers.

	Not at All	Somewhat	Moderately So	Very Much So
I feel pleasant	1	2	3	4
I feel nervous and restless	1	2	3	4
I feel satisfied with myself	1	2	3	4
I wish I could be as happy as others seem to be	1	2	3	4
I feel like a failure	1	2	3	4
I feel rested	1	2	3	4
I am calm, cool and collected	1	2	3	4
I feel that difficulties are piling up so that I cannot overcome them	1	2	3	4
I worry too much over something that doesn't really matter	1	2	3	4
I am happy	1	2	3	4
I have disturbing thoughts	1	2	3	4
I lack self confidence	1	2	3	4
I feel secure	1	2	3	4
I make decisions easily	1	2	3	4

I feel inadequate	1	2	3	4
I am content	1	2	3	4
Some unimportant thought runs through my mind and bothers me	1	2	3	4
I take disappointments so keenly that I can't put them out of my mind	1	2	3	4
I am a steady person	1	2	3	4
I get in a state of tension or turmoil as I think over my recent concerns and interests	1	2	3	4

## Appendix A9

### Mental Imagery Subscale of the Assessment of Illness Representations Revised

In this section we want to try and understand the mental images you have of your breast cancer prior to treatment. Many women have a mental image or picture in their minds of what their cancer “looks like” inside their bodies. It may be more of a symbolic or creative image that “pops into your mind” than a “realistic” or physically accurate image. We would like you to describe what this image looks like. You may like to describe aspects of this image including its color, texture, shape, size, position and whether or not it moves.

- A) Please describe the image you had of your cancer as it looked before your treatment (in your own words).

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## Appendix A10

### Short Form 36 Quality of Life Measure

In general would you say your health is:

- Excellent
- Very Good
- Good
- Fair
- Poor

Compared to one year ago, how would you rate your health in general now?

- Much better now than one year ago
- Somewhat better now than one year ago
- About the same as one year ago
- Somewhat worse than one year ago
- Much worse now than one year ago

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	<b>Yes, Limited a Lot</b>	<b>Yes, Limited a Little</b>	<b>No, Not Limited at All</b>
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports			
Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf			
Lifting or carrying groceries			
Climbing several flights of stairs			
Climbing one flight of stairs			
Bending, kneeling or stooping			
Walking more than a kilometre			
Walking several hundred metres			
Walking a hundred metres			
Bathing or dressing yourself			

During the past month, how much of the time have you had any of the following problems with your work or any other regular activities as a result of your physical health?

	All of the Time	Most of the Time	Some of the Time	A little of the time	None of the time
Cut down on the <b>amount of time</b> you spent on work or other activities					
<b>Accomplished less</b> than you would like					
Were limited in the <b>kind</b> of work or other activities					
<b>Had difficulty</b> performing the work or other activities (eg. it took extra effort)					

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

	All of the Time	Most of the Time	Some of the Time	A time of the time	None of the time
Cut down the <b>amount of time</b> you spent on work or other activities					
<b>Accomplished less</b> than you would like					
Didn't do work or other activities as <b>carefully</b> as usual					

During the past month, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups?

- Not at All
- Slightly
- Moderately
- Quite a Bit
- Extremely

How much bodily pain have you had during the past month?

- None
- Very Mild
- Mild
- Moderate
- Severe
- Very Severe

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

- Not at All
- A Little Bit
- Moderately
- Quite a Bit
- Extremely

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

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the Time
Did you feel full of life?						
Have you been very nervous?						
Have you felt so down in the dumps that nothing could cheer you up?						
Have you felt calm and peaceful?						

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you have a lot of energy?						
Have you felt downhearted and depressed?						
Did you feel worn out?						
Have you been happy?						
Did you feel tired?						

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

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time
- 

**How TRUE or FALSE is each of the following statements for you?**

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
I seem to get sick a little easier than other people					
I am as healthy as anybody I know					
I expect my health to get worse					
My health is excellent					

## Appendix A11 Illness Perceptions Questionnaire Revised

We are interested in your own personal views of breast cancer. Some statements may seem very similar, but please answer them all as the wording of a statement may make a difference in how people respond. Please check the box that indicates how much you agree or disagree with each of the following statements about your breast cancer.

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
My breast cancer lasted a short time					
My breast cancer is likely to be permanent rather than temporary					
My breast cancer will last for a long time					
My breast cancer passed quickly					
My breast cancer is gone					
I expect to have breast cancer for the rest of my life					
My breast cancer is a serious condition					
My breast cancer has had major consequences on my life					
My breast cancer does not have much effect on my life					
My breast cancer strongly affects the way others see me					
My breast cancer has had serious financial consequences					
My breast cancer has caused difficulties for those who are close to me					
There is a lot I can do to control the breast cancer and keep it from returning					
What I do can determine whether my breast cancer returns					

The course of my breast cancer depends on me					
Nothing I do will affect my risk for breast cancer recurrence.					
I have the power to influence my risk for breast cancer recurrence					
My actions will have no effect on the outcome of my breast cancer					
My condition will improve in time					
When a new symptom develops, I worry that the breast cancer has returned.					
Almost every new symptom makes me worry about the breast cancer coming back.					
My symptom experiences remind me of my risk for breast cancer recurrence.					
There is very little that can be done to improve my condition					
My treatment is effective in curing my breast cancer					
The negative effects of my breast cancer can be prevented (avoided) by my treatment					
My treatment can control my condition					
There is nothing that can help my condition					
The symptoms of my condition are puzzling to me					
My breast cancer is a mystery to me					
I don't understand my breast cancer					
My breast cancer doesn't make any sense to me					
I have a clear picture or understanding of my breast cancer					
The symptoms of my condition change a great deal from day to day.					
My symptoms come and go in cycles					

My breast cancer is very unpredictable					
I go through cycles in which my condition gets better or worse					
I get depressed when I think about my breast cancer					
When I think about my breast cancer I get upset					
My breast cancer makes me feel angry					
My breast cancer does no worry me					
Having breast cancer makes me feel anxious					
My breast cancer makes me feel afraid					

Below are a number of symptoms that you may or may not have had in the PAST WEEK. Please indicate by circling the response that indicates whether you believe that these symptoms are related to your breast cancer or breast cancer treatment.

	<b>I believe this symptom is related to my breast cancer (circle yes or no)</b>	
Aches or Pain	YES	NO
Sore Throat	YES	NO
Nausea	YES	NO
Breathlessness	YES	NO
Weight Loss	YES	NO
Fatigue/Tiredness	YES	NO
Headaches	YES	NO
Upset Stomach	YES	NO
Sleep Difficulties	YES	NO

Dizziness	YES	NO
Loss of Strength	YES	NO
Numb or Tingling Hands	YES	NO
Numb or Tingling Feet	YES	NO
Swollen Arms	YES	NO
Swollen Feet	YES	NO
Hot Flushes	YES	NO
Night Sweats	YES	NO
Appetite Changes	YES	NO
Pain in Breast	YES	NO
Unusual Lump or Bump	YES	NO
Constipation	YES	NO
Menstrual Changes	YES	NO
Tinnitus (Ringing in the Ears)	YES	NO
Cough	YES	NO

## Appendix B Pilot Study Consent Form



Building 721, Tamaki Campus  
Cnr Morrin & Merton Roads  
Glen Innes, Auckland, New Zealand  
Telephone 64 9 373 7599 x86886  
Facsimile 64 9 373 7902  
[www.psych.auckland.ac.nz](http://www.psych.auckland.ac.nz)

### Consent Form

(This consent form will be stored for a period of 10 years before it is destroyed)

**Project Title:** Coping with Worry of Cancer Recurrence

**Researchers:** Professor Linda Cameron and Loshni Rogers (Doctorate in Clinical Psychology Candidate)

- I have read and I understand the information sheet (12 August 2010) for volunteers taking part in the study designed to investigate how women are coping with their concerns of cancer recurrence. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I have had the opportunity to ask questions and understand the study, and I have been given time to consider whether to take part. I understand that, by submitting this consent form, I agree to take part in this research under the terms indicated in the Participant Information Sheet.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without giving a reason. My participation or non-participation in this research will also not affect my medical care or relationship with my health care professionals in any way.
- 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 I can request my questionnaire back by contacting the Principal Investigator.
- I understand that this consent form will be stored separately to any other data related to me. These will be stored and secured at the University of Auckland for ten years.
- I am 18 years or over.

- I have completed treatment for primary breast cancer in the last 5 years.
- I have not experienced a cancer relapse in this time.
- I am not currently seeking treatment for depression or any other psychiatric disorder.
- I give my permission for you to access information about my diagnosis and treatment from the cancer registry.

NAME: \_\_\_\_\_

SIGNED: \_\_\_\_\_

DATE: \_\_\_\_\_

- In order to maintain your privacy we would like you to choose a codename for yourself. You will enter this codename when completing the questionnaire for this study. Your codename should be something easy for you to remember e.g. the name of your pet. If you forget your codename please email me [loshnirogers@hotmail.com](mailto:loshnirogers@hotmail.com) and I will email you with it.

CODENAME: \_\_\_\_\_

- How would you like to complete the questionnaire? (please tick one box)
  - I prefer to fill out the questionnaire online by visiting <http://www.surveymonkey.com/s/bcsurvivors>

Or

- I prefer to have a hard copy posted out to me. If so please fill out your address below:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

- If you would you like to receive a summary of the results of the larger study titled ' Understanding Women's Experiences and Concerns Following Breast Cancer' please fill in your email or postal address below:

\_\_\_\_\_

\_\_\_\_\_

This study has received ethical approval from the Northern Regional Ethics Committee on 20/09/10 for one year. Reference NTX/10/04/023

## Appendix C Pilot Study Participant Information Sheet



Building 721, Tamaki Campus  
Cnr Morrin & Merton Roads  
Glen Innes, Auckland, New Zealand  
Telephone 64 9 373 7599 x86886  
Facsimile 64 9 373 7902  
[www.psych.auckland.ac.nz](http://www.psych.auckland.ac.nz)

### INFORMATION SHEET FOR POTENTIAL PARTICIPANTS

**Title:**

Coping with Worry of Cancer Recurrence

**Researchers:**

Professor Linda Cameron and Loshni Rogers, Doctorate (Clinical Psychology) candidate,  
Department of Psychology, University of Auckland

Hello,

My name is Loshni Rogers. I am currently doing my doctorate in Clinical Psychology at the University of Auckland. This research is part of my doctoral thesis.

You are invited to take part in a pilot study to investigate how women are coping with their concerns of cancer recurrence after they have completed treatment for primary breast cancer. This experience is common for many people after cancer treatment and it is hoped that a better understanding of this issue will help shape psychological services for helping women manage their concerns. This investigation is part of a larger study that will explore how women's worry of cancer recurrence impacts their mental wellbeing and quality of life. This pilot study involves the completion of a short questionnaire. If you wish to take part in this study, you can **either** complete the questionnaire included in this pack **or** complete it online at <http://www.surveymonkey.com/s/bcsurvivors>. A prepaid and addressed envelope has been included if you wish to fill out the questionnaire and post it back to us. Remember that your participation is entirely voluntary (your choice). You do not have to take part, and if you choose not to take part, this will not affect any future care or treatment at your clinic. If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason.

**Who will benefit from this study?**

This pilot study is part of a larger study designed to better understand women's experiences so that interventions may be put in place to improve the wellbeing of women following cancer treatment. The findings of this study will hopefully benefit future women with breast

cancer in several ways. It will identify how particular ideas or beliefs about cancer may affect psychological wellbeing and coping strategies that are most effective at reducing distress. This will help guide psychological services for women with breast cancer so that their adjustment following treatment is improved. It will also help identify women earlier in treatment who may be more susceptible to distress following treatment. The findings of this project will also be presented to the Breast Cancer Clinics involved in this study to inform them of how women are faring post-treatment. It is anticipated that this may improve aspects of the information as well as the communication women receive from medical professionals prior to treatment.

### **What does the study involve?**

Women who are over the age of 18 and have undergone treatment for primary breast cancer in the last 5 years will be invited to participate in this pilot study. We hope to have 60 participants for this project who will be recruited through Breast Cancer Clinics, and via the Cancer Registry.

Participants will be asked to complete one short questionnaire. This may be completed at home in your own time and you may choose to fill out **either** the hard copy included in this pack **or** complete it online at <http://www.surveymonkey.com/s/bcsurvivors>. The questionnaire should take about twenty minutes to complete. Please feel reassured that anything you say in your questionnaire will be kept confidential and private.

### **What will happen at the end of the study?**

Once the questionnaires is completed and returned by participants in this study, the results of the study will be analysed. No material that could personally identify you will be used in the write-up of the study. The findings of the larger study titled 'Understanding Women's Experiences and Concerns following Breast Cancer' will be sent to you either via post or email. The university requires that the information you give me is kept in secure storage for ten years after the completion of the study. After this time, all data stored in computer files will be deleted and all paper copies of data will be destroyed by shredding. No one except my research supervisor, a research assistant (who will be required to sign a confidentiality agreement) and I will have access to this information.

### **Are there any risks involved?**

Consideration of one's feelings about risk of cancer recurrence may be upsetting for some women and if, for any reason, the study brings up issues for you that are upsetting, please feel free at any time to contact me. I will provide you with information on how to access breast cancer support services. My contact details are provided below. I would be happy to answer any of your questions or concerns. Also, if we find that your results indicate clinical levels of depression or anxiety we will inform you of this and provide you with advice on what you can do. If necessary, I can help you to access the support you might require. If any issues arise that suggest your safety or someone else's safety may be at risk, I will need to talk about this with someone who I think can help reduce this risk.

### **What are your rights as a participant?**

Your participation is entirely voluntary (your choice). You do not have to take part in this study. If you do agree to take part, you are free to withdraw from the study at any time without having to give a reason. Please note, however, that your questionnaire responses cannot be withdrawn from the study after 31/07/11. You can contact either me or my supervisor, with any questions or concerns that you may have at any stage of the study.

My supervisor is Professor Linda Cameron (Psychology Department) from the University of Auckland. Her contact details are in the following section. If you want to make a complaint, you can address it to me, my supervisor, or the Administrator of the National Ethics Committee, at the address given in the following section.

### **Where can I get more information about the study?**

You can contact me by the phone number supplied below, leave a message for me and I will call you back as soon as I can. By replying, you are not committing yourself to the research. What you are agreeing to is giving me your contact details and allowing me to contact you to discuss whether you may like to participate. I would be very grateful if you could take the time to reply to me as soon as you have had enough time to think about this.

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 Advocate: 0800 555 050

Thank you for taking the time to read this information sheet and considering sharing your valuable knowledge with me. I hope I will hear from you soon.

Yours Sincerely,

Loshni Rogers

Loshni Rogers  
[loshnirogers@hotmail.com](mailto:loshnirogers@hotmail.com)  
 Psychology Department  
 University of Auckland  
 Private Bag 92019  
 Auckland

#### **Supervisor:**

Professor Linda Cameron  
 (09) 373-7999, extn.86869  
[l.cameron@auckland.ac.nz](mailto:l.cameron@auckland.ac.nz)  
 Psychology Department  
 University of Auckland  
 Private Bag 92109  
 Auckland

You may also contact the head of the Psychology Department:

Professor Fred Seymour  
Department of Psychology  
The University of Auckland  
Private Bag 92019  
Auckland  
Phone: (09) 373-7599 ext. 88414

**Other contact details:**

Health and Disability Consumer Advocate            0800 423 638

For any queries regarding ethical concern please contact the  
Administrator of the National Ethics Committee:  
Northern Y Regional Ethics Committee  
P.O Box 1031  
Hamilton  
(07) 858 7021

**This study has received ethical approval from the Northern X Regional Ethics Committee on 20/09/2010 for 1 year. Reference NTX/10/04/023**

**Compensation**

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation, and Compensation Act 2001. ACC cover is not automatic, and your case will need to be assessed by ACC according to the provisions of the Injury Prevention, Rehabilitation, and Compensation Act 2001. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors, such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses, and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators. If you have any questions about ACC, contact your nearest ACC office or the investigator. You are also advised to check whether participation in this study would affect any indemnity cover you have or are considering, such as medical insurance, life insurance and superannuation.

## Appendix D Main Study Consent Form



Building 721, Tamaki Campus  
Cnr Morrin & Merton Roads  
Glen Innes, Auckland, New Zealand  
Telephone 64 9 373 7599 x86886  
Facsimile 64 9 373 7902  
[www.psych.auckland.ac.nz](http://www.psych.auckland.ac.nz)

### Consent Form

(This consent form will be stored for a period of 10 years before it is destroyed)

**Project Title:** Understanding Women's Experiences and Concerns Following Breast Cancer

**Researchers:** Professor Linda Cameron and Loshni Rogers (Doctorate in Clinical Psychology Candidate)

- I have read and I understand the information sheet (12 August 2010) for volunteers taking part in the study designed to better understand women's experiences and their concerns about cancer recurrence after treatment for breast cancer. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I have had the opportunity to ask questions and understand the study, and I have been given time to consider whether to take part. I understand that, by submitting this consent form, I agree to take part in this research under the terms indicated in the Participant Information Sheet.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without giving a reason. My participation or non-participation in this research will also not affect my medical care or relationship with my health care professionals in any way.
- 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 I can request my questionnaires back by contacting the Principal Investigator.

- I understand that this consent form will be stored separately to any other data related to me. These will be stored and secured at the University of Auckland for ten years.
- I am 18 years or over.
- I have completed treatment for primary breast cancer in the last 36 months.
- I have not experienced a cancer relapse in this time.
- I am not currently seeking treatment for depression or any other psychological disorder.
- I give my permission for you to access information about my diagnosis and treatment from the cancer registry.

NAME: \_\_\_\_\_

ADDRESS (To send you each questionnaire): \_\_\_\_\_

\_\_\_\_\_

SIGNED: \_\_\_\_\_

DATE: \_\_\_\_\_

- In order to maintain your privacy we would like you to choose a codename for yourself. You will enter this codename when completing the questionnaires for this study. Your codename should be something easy for you to remember e.g. the name of your pet. If you forget your codename please email me [loshnirogers@hotmail.com](mailto:loshnirogers@hotmail.com) and I will email you with it.

CODENAME: \_\_\_\_\_

- I would like to be **emailed/ texted/called** (please circle one) to remind me to complete each questionnaire. The second questionnaire is to be completed one month following the first questionnaire.

My email/phone number is: \_\_\_\_\_

- If you would you like to receive a summary of the results on completion of this study please fill in your email or postal address below:

\_\_\_\_\_

\_\_\_\_\_

**This study has received ethical approval from the Northern X Regional Ethics Committee on 20/09/2010 for 1 year. Reference NTX/10/04/023.**

## Appendix E

### Main Study Participant Information Sheet



**NEW ZEALAND**

Te Whare Wānanga o Tāmaki Makaurau

Building 721, Tamaki Campus

Cnr Morrin & Merton Roads

Glen Innes, Auckland, New Zealand

Telephone 64 9 373 7599 x86886

Facsimile 64 9 373 7902

[www.psych.auckland.ac.nz](http://www.psych.auckland.ac.nz)

### **INFORMATION SHEET FOR POTENTIAL PARTICIPANTS**

**Title:**

Understanding Women's Experiences and Concerns Following Breast Cancer

**Researchers:**

Professor Linda Cameron and Loshni Rogers, Doctorate (Clinical Psychology) candidate, Department of Psychology, University of Auckland

Hello,

My name is Loshni Rogers. I am currently doing my doctorate in Clinical Psychology at the University of Auckland. This research is part of my doctoral thesis.

You are invited to take part in a study to investigate women's experiences following breast cancer treatment. We are particularly interested in women's concerns about cancer returning after they have completed treatment for primary breast cancer. This experience is common for many people after cancer treatment and it is hoped that a better understanding of this issue will help shape psychological services for helping women manage their concerns.

For the purposes of this investigation, we are interested in some of your cancer related beliefs, how you are coping with any concerns you may have, and also how you are doing in general. There are two questionnaires that address these aspects, which will help us better understand how you have been faring since your treatment. Remember that your participation is entirely voluntary (your choice). You do not have to take part, and if you choose not to take part, this will not affect any future care or treatment at your clinic. If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason.

**Who will benefit from this study?**

The purpose of this study is to better understand women's experiences so that interventions may be put in place to improve the wellbeing of women following cancer treatment. The findings of this study will hopefully benefit future women with breast cancer in several ways. It will identify how particular ideas or beliefs about cancer may affect psychological wellbeing and coping strategies that are most effective at reducing distress. This will help

guide psychological services for women with breast cancer so that their adjustment following treatment is improved. It will also help identify women earlier in treatment who may be more susceptible to distress following treatment. The findings of this project will also be presented to the Breast Cancer Clinics involved in this study to inform them of how women are faring post-treatment. It is anticipated that this may improve aspects of the information as well as the communication women receive from medical professionals prior to treatment.

### **What does the study involve?**

Women who are over the age of 18 and have undergone treatment for primary breast cancer in the last 3 years will be invited to participate in this study. We hope to have 130 participants for this project who will be recruited through Auckland Breast Cancer Clinics, and via the Cancer Registry.

Participants will be asked to complete two questionnaires. **If you would like to participate in this study, please complete the consent form provided in this pack and post it back to us using the pre-paid envelop which is also included in this pack.** Once we have received your consent form we will post you the first questionnaire with a pre-paid return envelope. The second questionnaire will also be posted to you in a month's time. The first questionnaire is comprised of different sections asking you about your mental well being, quality of life, perceptions of breast cancer, coping strategies, communication with medical professionals, cancer concerns, and the positive and negative consequences of your experience with cancer.

The second questionnaire is to be completed one month after you have completed the first. It is a shorter questionnaire comprising of seven parts that focus on your mental well being, quality of life, positive outcomes, and the negative impacts of cancer. We will provide a reminder to you at this time either by post, email or telephone, whichever is preferable to you. Each questionnaire should take between one to one and a half hours to complete. Please feel reassured that anything you say in your questionnaire will be kept confidential and private.

### **What will happen at the end of the study?**

Once both questionnaires are completed and returned by participants in this study, the results of the study will be analysed. No material that could personally identify you will be used in the write-up of the study. The findings of this study will be sent to you either via post or email. No one except my research supervisor, a research assistant (who will be required to sign a confidentiality agreement) and I will have access to this information. The university requires that the information you give me is kept in secure storage for ten after the completion of the study. After this time all data stored in computer files will be deleted and all paper versions of data you have provided will be destroyed.

### **Are there any risks involved?**

Consideration of one's feelings about risk of cancer recurrence may be upsetting for some women and if, for any reason, the study brings up issues for you that are upsetting, please feel free at any time to contact me. I will provide you with information on how to access breast cancer support services. My contact details are provided below. I would be happy to answer any of your questions or concerns. Also, if we find that your results indicate clinical levels of depression or anxiety we will inform you of this and provide you with advice on what you can do. If necessary, I can help you to access the

support you might require. If any issues arise that suggest your safety or someone else's safety may be at risk, I will need to talk about this with someone who I think can help reduce this risk.

**What are your rights as a participant?**

Your participation is entirely voluntary (your choice). You do not have to take part in this study. If you do agree to take part, you are free to withdraw from the study at any time without having to give a reason. Please note, however, that your questionnaire responses cannot be withdrawn from the study after 31/12/11.

My supervisor is Professor Linda Cameron (Psychology Department) from the University of Auckland. Her contact details are in the following section. If you want to make a complaint, you can address it to me, my supervisor, or the Administrator of the National Ethics Committee, at the address given in the following section.

**Where can I get more information about the study?**

You can contact me by the phone number supplied below, leave a message for me and I will call you back as soon as I can. By replying, you are not committing yourself to the research. What you are agreeing to is giving me your contact details and allowing me to contact you to discuss whether you may like to participate. I would be very grateful if you could take the time to reply to me as soon as you have had enough time to think about this.

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 Advocate: 0800 555 050

Thank you for taking the time to read this information sheet and considering sharing your valuable knowledge with me. I hope I will hear from you soon. If you would like to participate, please don't forget to complete the consent form and send it back to us using the pre-paid envelope.

Yours Sincerely,

Loshni Rogers

**Principal Investigator:**

Loshni Rogers  
[loshnirogers@hotmail.com](mailto:loshnirogers@hotmail.com)  
Psychology Department  
University of Auckland  
Private Bag 92019  
Auckland

**Supervisor:**

Professor Linda Cameron  
(09) 373-7999, extn.86869  
[l.cameron@auckland.ac.nz](mailto:l.cameron@auckland.ac.nz)  
Psychology Department  
University of Auckland

Private Bag 92109  
Auckland

You may also contact the head of the Psychology Department:

Professor Fred Seymour  
Department of Psychology  
The University of Auckland  
Private Bag 92019  
Auckland  
Phone: (09) 373-7599 ext. 88414

**Other contact details:**

For any queries regarding ethical concern please contact the Administrator of the National Ethics Committee:

Northern X Regional Ethics Committee  
Ministry of Health  
3<sup>rd</sup> Floor, Unisys Building  
650 Great South Road  
Penrose  
Auckland

**This study has received ethical approval from the Northern X Regional Ethics Committee on 20/09/2010 for 1 year. Reference NTX/10/04/023.**

**Compensation**

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation, and Compensation Act 2001. ACC cover is not automatic, and your case will need to be assessed by ACC according to the provisions of the Injury Prevention, Rehabilitation, and Compensation Act 2001. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors, such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses, and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators. If you have any questions about ACC, contact your nearest ACC office or the investigator. You are also advised to check whether participation in this study would affect any indemnity cover you have or are considering, such as medical insurance, life insurance and superannuation.

