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AN EVALUATION OF THE INFLUENCE OF PERCEPTIONS OF BREAST CANCER ON DISTRESS IN IRISH WOMEN

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Thesis submitted to the National University of Ireland, Galway in fulfilment of the requirements for the Degree of Doctor of Philosophy (Psychology)

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ABSTRACT

Breast cancer is the most common form of invasive cancer diagnosed in women in Ireland. It can cause distress in healthy women considering their risk of developing the disease, as well as in women who have been diagnosed with breast cancer. The Self-Regulatory Model of Illness Behaviour (SRM; Leventhal, Meyer, & Nerenz, 1980) asserts that perceptions of an illness can impact upon an individuals’ response to a health threat. This series of studies assessed the role of the Self-Regulatory model, and specifically illness perceptions, in determining breast cancer-related distress in both healthy women and women with breast cancer.

Study 1a): Risk and illness perceptions, breast cancer worry and screening intentions in healthy women

Study 1a) examined the predictive ability of risk perceptions and illness perceptions in determining breast cancer worry and breast cancer screening intentions in healthy women. Nine hundred and forty eight women from the community completed measures of risk perceptions, illness perceptions, cancer-related worry, frequency of breast self-examination, and intentions to attend breast cancer screening. Hierarchical regression analyses revealed that holding higher perceptions of risk predicted 17% of the variance in breast cancer worry, whilst a greater understanding of breast cancer, more negative emotional representations, and a more chronic timeline, predicted 14% of the variance in breast cancer worry. Intentions to attend a breast cancer screening programme and perform breast self-examination (BSE) were poorly predicted by the variables. Mediation analyses revealed that risk perceptions partially mediated the relationship between illness perceptions and breast cancer worry. Risk and illness perceptions were also assessed in women with and without a family history of breast cancer, controlling for breast cancer worry. One way between-subjects ANCOVAs indicated that women with a family history of breast cancer had a higher understanding of breast cancer, and higher risk perceptions, than women without a family history. Although women may hold very negative perceptions of breast cancer, it may not lead to increased worry, unless women also hold high perceptions of risk of developing the disease. Given that the variance explained was moderate, further work is needed to determine the
influence of these variables on worry and screening intentions. Despite this, the findings provide novel evidence that both illness and risk perceptions are predictors of breast cancer worry in women from the general population, and emphasise the importance of measuring both a person’s perception of their risk, as well as their emotional and behavioural responses to an illness threat.

**Study 1b): Illness perceptions and distress in healthy women and women with breast cancer**

According to the Self-Regulatory Model, illness perceptions differ based on the level of experience to an illness (Buick & Petrie, 2002). Study 1b) examined differences in illness perceptions in women with varying levels of experience with breast cancer. Ninety nine healthy women from Study 1a) were divided into those with and without a family history of breast cancer, and sixty women who had themselves been diagnosed with breast cancer, completed measures of illness perceptions, cancer-related worry, and general distress. A series of one-way between-subjects ANOVAs revealed significant differences in cancer worry, chronic timeline, consequences and external causes. Healthy women with a family history of breast cancer reported lower levels of cancer-related worry, whilst women without a family history of breast cancer reported higher external causal attributions. Women with breast cancer had lower chronic timeline beliefs and greater perceived consequences than healthy women with and without a family history. There was also a trend that healthy women with a family history reported more illness coherence. Results suggest that healthy women’s perceptions of breast cancer may not be accurate representations of the actual experience of the disease, and that illness perceptions may be fully developed before individuals are diagnosed with an illness. These results highlight the importance of measuring illness perceptions in healthy women, as holding views that are at variance with medical opinion may lead to lower adherence to mammography screening, and more negative responses to a subsequent diagnosis of breast cancer.

**Study 2: Illness perceptions and coping in women with breast cancer**

Study 2 assessed the relative contribution of demographic, medical, and psychological variables in distress in women with breast cancer at diagnosis and 12 months post-diagnosis. Specifically, illness perceptions and coping, within the
framework of the SRM, were assessed to examine their influence on distress. One hundred and five women completed measures of medical information, perceived stress, illness perceptions, coping, and distress at diagnosis; and 57 of these women completed measures of distress 12 months post-diagnosis. Hierarchical regressions revealed that, at diagnosis, controlling for medical variables, perceived stress predicted between 9-33% of the variance in distress, whilst illness perceptions accounted for 7-29% of the variance in general and cancer-related distress. Higher perceived control predicted greater depression, whilst higher illness coherence was related to less anxiety and cancer-related distress. Coping had less impact on cancer-related distress than illness perceptions; high levels of anxious preoccupation and low fighting spirit only explained 5% of the variance in cancer-related distress at diagnosis. At 12 months post-diagnosis, baseline levels of illness perceptions failed to explain any of the variance, whilst coping accounted for 9% of the variance in cancer-related distress. Analyses also revealed that anxious preoccupation mediated the relationship between illness perceptions and cancer-related distress. The results underscore the importance of the inclusion of appraisal of stress in women with breast cancer, as previous stressful events may influence how women respond to a subsequent diagnosis. The findings also provide evidence that variables from the Self-Regulatory model are a useful framework to explain distress in relation to breast cancer. Illness perceptions were far more useful than coping in explaining distress in women with breast cancer at diagnosis, whilst coping had a continued influence on cancer-related distress over time. In addition, the impact of illness perceptions on distress was mediated by coping. These results reflect the complexities of the relationship of illness perceptions and coping in the model, and highlight the importance of measuring coping when examining illness perceptions and distress.

Study 3: Coping with chemotherapy for breast cancer: A qualitative study

Study 3 explored the role of coping and coping appraisal in breast cancer treatment. Twenty women diagnosed with breast cancer who required chemotherapy as part of their treatment were interviewed about their coping strategies and their effectiveness during chemotherapy. Thematic analyses were conducted to identify the types of coping strategies women employed to deal with chemotherapy. Women engaged in a number of strategies to deal with the side effects of treatment. Behavioural coping strategies such as anticipatory coping, seeking information, and
maintaining routine activities were used to regain a sense of control. At the same time, emotional coping strategies were utilised to cope with treatment-related distress. Emotional expression, seeking social support and reappraisal were most commonly reported. In addition, women engaged in coping appraisal, which influenced distress levels. The findings indicate that a combination of coping strategies is important in dealing with the side effects of chemotherapy. Anticipating side effects and engaging in strategies to minimise their impact highlights the importance of the provision of accurate information of the side effects of treatment, and the potential for these strategies as components of effective interventions to reduce distress in women receiving chemotherapy.

In sum, the studies provide support that the components of the Self-Regulatory Model of Illness Behaviour, most notably illness perceptions, are predictors of distress in both healthy women and women with breast cancer. The research highlights the importance of measuring both illness perceptions and coping together, and emphasises the value of components of the Self-Regulatory Model as a framework to develop future interventions to reduce cancer-related distress.
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ABBREVIATIONS/ACRONYMS

AIRR Assessment of Illness Risk Representations
ANCOVA Analysis of Covariance
ANOVA Analysis of Variance
BIPQ Brief Illness Perception Questionnaire
BSE Breast self-examination
DCIS Ductal carcinoma in situ
HADS Hospital Anxiety and Depression Scale
HIV Human immunodeficiency virus
IBD Inflammatory bowel disease
IDC Invasive ductal carcinoma
IES Impact of Events Scale
ILC Invasive lobular carcinoma
IMIQ Implicit Models of Illness Questionnaire
IPQ Illness Perception Questionnaire
IPQ-R The Revised Illness Perception Questionnaire
KMO Kaiser-Meyer-Olin value
LCIS Lobular carcinoma in situ
LIN Lobular in situ neoplasia
LOT Life Orientation Test
MAC The Mental Adjustment to Cancer Scale
MI Myocardial infarction
MS Multiple sclerosis
PCA Principal components analysis
PMDI Personal Models of Diabetes Interview
PSS Perceived Stress Scale
RA Rheumatoid arthritis
RCT Randomised controlled trial
SRM Self-Regulatory Model of Illness Behaviour
STAI State-Trait Anxiety Inventory
Breast cancer is the most common form of cancer in women, with over 1.38 million women diagnosed worldwide in 2008, accounting for 23% of all new cancer cases (Jemal, Center, Desantis, & Ward, 2010). Breast cancer affects primarily women, but a small number of men are also diagnosed each year. It is estimated that the lifetime risk for men is 0.11%, whilst the risk is 13% for women (Brewster & Helzlsouer, 2001). The most common symptoms of breast cancer are a lump, changes in shape or colour to the breast or nipple, changes such as dimpling and inversion of the nipple, and pain and swelling in the breast or armpit. A number of risk factors have been implicated in the development of breast cancer, and screening initiatives have been developed to increase early detection.

**Nature of Breast Cancer**

Breast cancer encompasses many different types of cancers that affect the breasts. The two most common types of breast cancer are non-invasive cancer, and invasive cancer. Non-invasive breast cancer is disease that is contained in the breast tissue. It can be categorised by its location in mammary ducts (ductal carcinoma in situ, DCIS) or lobules (lobular carcinoma in situ, LCIS; lobular in-situ neoplasia, LIN). Invasive cancer is cancer that has spread to nearby tissue, lymph nodes under the arm, or other organs. It can also be further divided into cancer that spreads from the ducts (invasive ductal carcinoma; IDC) or lobules (invasive lobular carcinoma; ILC). Invasive ductal cancer (IDC) is more common, accounting for up to 73% of all breast cancers, whilst lobular cancers account for approximately 15.60% of all breast cancers in the United States (Li, Anderson, Daling, & Moe, 2003).

**Breast Cancer in Ireland**

In Ireland, breast cancer is the most common cancer diagnosed in women (National Cancer Registry, Ireland, 2011), accounting for 29% of all invasive cancers diagnosed in women between 2000 and 2004 (Donnelly, Gavin, & Comber,
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2009), and 32.30% of all invasive cancers from 2007 to 2009 (National Cancer Registry, Ireland, 2011). Ireland has the fourth highest incidence rate of breast cancer compared to 30 other European countries, after Belgium, France, and the Netherlands. Increases in incidence rates have coincided with the availability of national breast cancer screening programmes, but mortality rates have declined since 1989 (Autier, et al., 2010). In Ireland, women have a 10% risk of developing breast cancer by the age of 75, whilst men have a 0.10% risk of developing the disease (National Cancer Registry, Ireland, 2011).

An average of 650 women die each year from the disease (Central Statistics Office, 2012), and it accounts for 15.80% of all cancer-related deaths in Ireland (National Cancer Registry, Ireland, 2011). Ireland holds the fourth highest mortality rate in Europe for breast cancer; survival rates were ranked 16th out of the 20 countries assessed (National Cancer Registry, Ireland, 2011). Five-year survival rates in women were 77.10% for Ireland between 1994 and 2004 (Donnelly et al. 2009); and increased to 82% in 2007 to 2009 (National Cancer Registry, Ireland, 2011).

Risk Factors

A great deal of research has examined the risk factors for developing breast cancer. The mean age of diagnosis in Ireland is 59 years (Donnelly et al., 2009), and research suggests that older age is a risk factor for developing breast cancer (Brunet, 2010). Having a family history of breast cancer is also considered to be one of the strongest risk factors for developing the disease (Brunet, 2010). In line with this, women who are over 40 and who have one or more family members diagnosed with breast cancer are at increased risk (Anderson & Badzioch, 1985). Furthermore, women who have at least one family member diagnosed with the disease have a greater risk of developing breast cancer in the future; with the risk of developing the disease increasing with the more family members affected.

Women who have a family history of breast cancer may inherit their risk through the presence of BCRA1 and BCRA2 gene mutations. The presence of a BCRA1 or BCRA2 mutation can increase the risk of developing breast and ovarian cancer (Ford, Easton, Bishop, Narod, & Goldgar, 1994). The cumulative risk of developing breast cancer by the age of 70 in individuals who carry this mutation is 50-87% (Ford et al., 1994; Ford et al., 1998). Although hereditary is considered to be
a strong risk factor for developing breast cancer (Wang, Miller, Egleston, Hay, & Weinberg, 2010), it only accounts for 5-10% of all breast cancers (Rees, Fry, Cull, & Sutton, 2004). Other factors, therefore, also influence the risk of developing the disease.

Lifestyle factors such as weight, diet, smoking, and exercise have been implicated as causal factors, but the evidence is mixed (Brewster & Helzlsouer, 2001; Friedman et al., 2007). McTiernan (2003) reviewed the evidence for behavioural causes of breast cancer, and found that a sedentary lifestyle, greater central adiposity, and alcohol use have the most evidence for increasing the risk of developing breast cancer. Obesity and alcohol use have been confirmed as possible risk factors for developing breast cancer in other studies (Berliner & Fay, 2007). The protective ability of modifying these behaviours; however, were not consistently supported (McTiernan, 2003), indicating that changing behaviour may not significantly reduce the risk of developing the disease. Early age at menarche, menopause after the age of 55, not having children, or having children after the age of 30, as well as the use of hormone replacement therapy, have been implicated as risk factors for developing the disease (Berliner & Fay, 2007). This highlights the potential risk-inducing effects of reproductive and hormonal factors (Brewster & Helzlsouer, 2001). Most breast cancers are receptive to hormones such as oestrogen and progesterone, so the presence of these factors may increase risk of breast cancer development in the future. Despite this, roughly 12-17% of breast cancers are ‘triple negative’; these cancers are not receptive to any hormones (Foulkes, Smith, & Reis-Filho, 2010). These risk factors have little or no influence on the development of this type of cancer, so the identification of them will only lead to predictions of who may be at risk of hormone-receptive disease.

**Screening for Breast Cancer**

Population-based screening for breast cancer has been made available in many countries in an attempt to lower mortality rates through early detection of the disease (Perry et al., 2008). Most screening programmes offer women mammograms every two years between the ages of 50 and 69 years, in line with European guidelines (Perry et al., 2008; Shapiro et al., 1998). Hakama, Coleman, Alexe, and Auvinen (2008) report acceptance rates of up to 80% across European screening
programmes, with recall rates for further testing and possible diagnoses between 1-8%.

Population-based screening for women aged 50-64 has been available for women in Northern Ireland since the 1990s, and screens more than 70% of those women invited (Autier, Boniol, Gavin, & Vatten, 2011). A similar programme was implemented in February 2000 in the Republic of Ireland. BreastCheck invites women aged 50-64 to attend mammography screening every two years. Since its inception and up to November 2011, BreastCheck has screened 368,851 women and detected 5,071 breast cancers, and has a 71.60% acceptance rate (National Cancer Screening Service, BreastCheck, 2011).

The emergence of national screening programmes (such as BreastCheck in Ireland, and the Breast Screening Programme in the UK) allows for the diagnosis of cancers at earlier stages, leading to better prognosis and less invasive treatments being required. Mammography screening programmes have reported reductions in mortality rates between 20-35% in women aged 50-69 years (Hakama, Coleman, Alexe, & Auvinen, 2008). Although screening is considered to be beneficial for reducing mortality, Autier, Boniol, Gavin and Vatten (2011) note that there are no differences in mortality rates between countries that do and do not have national mammography screening services. This may stem from a lack of prospective data, as many screening programmes have only been made available in the past number of years, so the benefits of these services may not yet be fully assessed. Despite the inconsistent results regarding reductions in mortality, screening is effective in early detection in the general population, and in reducing the necessity for more invasive treatment.

Treatment for Breast Cancer

Breast cancer accounted for 14% of the total number of cancer deaths worldwide in 2008 (Jemal et al., 2010). Despite this, advances in treatment and technology have led to reductions in mortality rates in women with breast cancer across 20 countries from 1950 to 1992 (Hermon & Beral, 1996), and reductions by a median of 19% across Europe from 1989 to 2006 (Autier, et al., 2010). Effective treatments are available for breast cancer, and traditionally include surgery. Surgery involves the removal of either part of the breast (lumpectomy, or breast conserving
surgery) or the whole of the breast (mastectomy). Surgery may also include removal of some or all of the lymph glands under the arm (axillary clearance) if the disease affects the area. For women who receive a mastectomy, reconstruction of the breast can be immediate (during initial surgery to remove the tumour) or delayed (conducted as a subsequent surgery). Treatment also includes radiotherapy, chemotherapy and hormone or endocrine therapy. From 2004 to 2008, 84% of women diagnosed with breast cancer in Ireland were treated with surgery, 61% received radiotherapy, 49% of women received chemotherapy, and 49% of women also received hormone treatment (National Cancer Registry, Ireland, 2011).

Radiotherapy involves the use of targeted radiation to destroy tumour cells in an affected area. It is often recommended in conjunction with breast conserving surgery such as lumpectomy in women with breast cancer. Van den Steene, Soete, and Storm (2000) assessed 36 trials of radiotherapy in women with breast cancer, and found that it improves overall survival, but can lead to many side effects such as sensation changes, burns, skin discoloration, swelling, and fatigue (Knobf & Sun, 2005).

Hormone therapy is offered to women whose tumour is receptive to oestrogen or progesterone. To prevent recurrence, women are recommended to take hormone drugs such as Tamoxifen, Femara, or Arimidex for five years post-diagnosis. These drugs are effective in preventing recurrence (Early Breast Cancer Trialists’ Collaborative Group, 2005), but can also lead to side effects, such as joint pain, digestive problems, and fatigue (Baum et al., 2002). Their use can also induce early menopause (Anderson et al., 2011).

Chemotherapy involves administering cytotoxic drugs as a systemic treatment for breast cancer. The drugs destroy any tumour cells throughout the body, and have been a standard treatment for cancer for a number of years. The side effects experienced from chemotherapy can be severe, but medical improvements and the availability of medication to minimise side effects, has led to better tolerance of the treatment. Moreover, recent advances have led to a reduction in women receiving chemotherapy. For example, Oncotype DX™testing is an assay test that categorises the risk of disease recurrence in women with the disease as low, intermediate, or high, based on the expression of 21 genes (Paik et al., 2004). It is used as a guide for recommending chemotherapy based on this risk, and has led to reductions in the number of women receiving chemotherapy (Ademuyiwa et al., 2011). In addition,
advances in surgical procedures and the availability of chemotherapy before surgery to reduce the size of the tumour (neoadjuvant chemotherapy) has led to a reduction in women receiving mastectomy, and an increase in women receiving a lumpectomy, or breast conserving surgery (Fisher et al., 1998). Although this is a less invasive operation, women who receive this surgery will often receive recommendations for attending up to seven weeks of daily radiotherapy.

Psychological Impact of Breast Cancer

Although the mortality rates of breast cancer are decreasing, and medical advances have led to more effective and less invasive treatments, breast cancer has a significant impact on women’s distress and psychological functioning. The diagnosis of breast cancer is a life-threatening event; distress is a common response to a cancer diagnosis (Baker et al., 2012). Research has therefore focused on the examination of distress experienced in women diagnosed with breast cancer.

Distress at diagnosis

Distress is prevalent in patients with cancer; for example Zabora and colleagues (Zabora, Brintsenhofeszoc, Curbow, Hooker, & Piantadosi, 2001) found that clinical levels of distress in cancer patients in the US ranged from 29.60% to 43.40%. In a study with 2,595 women with breast cancer, 17% reached the cut-off for clinical depression up to 4 years post-diagnosis (Bardwell et al., 2006), whilst in a sample of 1249 Austrian breast cancer patients, 32.80% reported clinical levels of distress up to three years post-diagnosis (Meraner et al., 2009). Further research on women diagnosed within the first year have reported clinical levels of anxiety ranging from 14-60%, whilst clinical scores of depression range from 6-17% across European samples (Høyer et al., 2011; Thuné-Boyle, Stygall, Keshgtar, Davidson, & Newman, 2012). Moreover, women who are diagnosed report increased anxiety and fear for the future (Garofalo, Choppala, Hamann, & Gjerde, 2009; Koch, Jansen, Brenner & Arndt, 2012).

Although distress is pronounced at diagnosis, these scores are not sustained over time. Significant reductions in anxiety and depression were reported in women with breast cancer from pre to post surgery (Groarke, Curtis, & Kerin, 2011).
Burgess and colleagues (2005) measured anxiety and depression in 150 women with breast cancer over 5 years. They reported that nearly 50% of women reported depression, anxiety, or both in the first year, which fell to 25% in the next three years, falling to 15% five years post-diagnosis. Kennedy, Harcourt, Rumsey, and White (2010) reported clinical anxiety as 39.50% at baseline, 11.60% at 6 months, and 11.90% at 9 months in 43 women with DCIS. Depression scores were considerably lower, with 14.00% at baseline, 4.70% at 6 months, and 7.10% at 9 months follow-up.

These results suggest that women will experience high levels of distress in the first year since diagnosis, but will decrease over subsequent years (van’t Spijker, Trijsburg & Duivenvoorden, 1997). The assessment of distress is important in that it can predict recovery from surgery (Miró & Raich, 1999), the experience of symptoms during treatment (Walker et al., 1999; Watson, Meyer, Thomson, & Osofsky, 1998), and has also been implicated in predicting immune functioning (Blomberg et al., 2009). At the same time, only 20% of Canadian cancer patients reported accessing psychosocial services during the first year since diagnosis (Carlson, Waller, Groff, Giese-Davis, & Bultz, 2011).

**Distress during treatment**

Due to the advances in medical treatment, more women are being treated successfully and surviving longer (Chu et al., 1996). This also leads to more issues relating to quality of life and adjustment (Alfano & Rowland, 2006). Treatment can lead to secondary problems such as lymphoedema (the accumulation of lymph in soft tissue with accompanying swelling in the arm, caused by the removal of lymph glands), radiation burns, as well as more psychosocial issues such as fatigue and the inability to return to work (Luoma & Hakamies-Blomqvist, 2004). All of these complications can lead to increased distress (Farrell, Heaven, Beaver, & Maguire, 2005).

There are many reasons why women who are diagnosed with cancer become distressed. Treatment factors have been examined for their influence, but do not consistently explain a large proportion of distress (Burgess, Ramirez, Richards, & Potts, 2002; Härtl et al., 2010; Rakovitch et al., 2003; Trimmel, Semrad, Kubista, Steger, & Zielinski, 2005). For example, although type of breast cancer has been
indicated as a predictor of distress, studies such as those of Lauzier and colleagues (Lauzier et al., 2010) report no differences in psychological state at one, six, or twelve month follow-up in 800 women with breast cancer. Similarly, receiving a mastectomy can negatively affect body image (Avis, Crawford, & Manuel, 2004; Janz et al., 2005; Moreira & Canavarro, 2010) and sexual functioning (Margolis, Goodman, & Rubin, 1990); but does not necessarily predict poorer psychological adjustment (Epping-Jordan et al., 1999; Kennedy, Harcourt, Rumsey, & White, 2010; Moreira & Canavarro, 2010; Nissen et al., 2001; van der Pompe, Antoni, Visser, & Garssen, 1996). In a meta-analysis assessing the psychosocial impact of surgery type, Moyer (1997) reported only minor advantages to receiving breast conserving surgery over mastectomy.

The inconsistencies in the effects of these disease factors may be explained in part by lack of knowledge of patients of their disease status. Many women are unaware of their current medical status, including their stage of disease or even their specific diagnosis (De Morgan, Redman, White, Cakir, & Boyages, 2002; Rabin, Leventhal, & Goodin, 2004). Objective measures of disease may not be good predictors of distress when women’s knowledge about their disease is inaccurate (Pieterse, Jager, Smets, & Henselmans, 2012). In addition, the predictive value of disease factors disappear when psychosocial factors are included (Bardwell et al., 2006), indicating that other treatment and psychological factors may be more important in how women respond to a diagnosis of breast cancer.

The physical limitations caused by treatment can have a negative impact on distress (Farrell et al., 2005). For example, chemotherapy is a common treatment for breast cancer, but it creates many challenges to women through the experience of side effects. Chemotherapy is important to examine in that many women report high levels of anticipatory anxiety (Jacobsen, Bovbjerg, & Redd, 1993). The side effects experienced from chemotherapy vary in both severity and frequency, but can include hair loss, fatigue, skin and nail problems, neuro-cognitive difficulties, pain, nausea and vomiting, mouth ulcers, and digestive problems (Carey et al., 2006). These side effects lead to reduced ability to work and engagement in normal activities (Luoma & Hakamies-Blomqvist, 2004), as well as potentially affecting delivery of medical care (Kreling, Figueiredo, Sheppard, & Mandelblatt, 2006).

Up to 90% of patients who require chemotherapy report some level of distress and discomfort (Costanzo et al., 2007; Love, Leventhal, Easterling,
Nerenz, 1989). It can also lead to further issues such as sustained distress, lower functioning, and fatigue after completion of treatment (Buick et al., 2000; Fan et al., 2005). Similarly, women who receive chemotherapy may report more depression, anger, and mood disturbance twelve weeks post-treatment (Hack et al., 2010).

Advances in medical care such as the emergence of OncoType DX™ testing, has led to less women receiving chemotherapy, but the increasing number of women being diagnosed with breast cancer leads to a greater need to examine how women deal with treatment (Rabin et al., 2004). Understanding the challenges faced when receiving chemotherapy, and the ways in which women attempt to minimise these challenges is, therefore, important.

**Summary**

Breast cancer is a common form of cancer, and is the most common cancer diagnosed in women in Ireland. The number of risk factors implicated for breast cancer highlights the lack of knowledge as to how to effectively prevent development of the disease. National screening programmes are becoming available worldwide, and are effective in the early detection of breast cancer, as well as potentially increasing prognosis and minimising the necessity for invasive treatment. A variety of effective treatments are available in women who develop breast cancer, including surgery, radiotherapy, chemotherapy, and hormone therapy. These treatments, although effective, may pose particular challenges to women receiving them.

Although effective treatment is available, a diagnosis of breast cancer can lead to heightened distress. The level of distress experienced may vary depending on the medical aspects of the disease, such as the treatment required. High levels of distress can impact on recovery, whilst the impact of treatment can have a detrimental effect on psychological functioning. Further research is needed to assess how women respond to the disease, so that adequate services can be provided and programmes to reduce distress can be developed.
CHAPTER 2: THE SELF-REGULATORY MODEL OF ILLNESS 
BEHAVIOUR

The Parallel Processing Model

An important area of illness research in health psychology to date relates to factors that influence health behaviours and distress. The way in which illness is conceptualised is an important question which has received much research attention as a potential predictor of behaviour and distress, and a number of theoretical models have been proposed to explain the process of how illness is understood.

The most common theory proposed to explain conceptualisations of illness, and how these influence distress and behaviour, is the Self-Regulatory Model of Illness Behaviour, previously known as the Common Sense Model of Illness Representations (Leventhal, 1970; Leventhal, Meyer, & Nerenz, 1980). The model assumes that patients are active problem solvers and are motivated to deal with illness threats. It is considered both a common sense model and a self-regulation model because it focuses on personal beliefs about illness, and explains how people monitor and change their behaviour to reach health-related goals (Cameron & Leventhal, 2003).

The model emerged from a series of studies relating to fear communication (Leventhal, 1970). Leventhal (1970) proposed that traditional models that consider fear as a drive do not take into account the failure of high fear messages to persuade individuals to change their behaviour. Leventhal suggested instead that fear and persuasion are related; however, the strength of this association may change over time. The paradigm can be seen as a framework for both fear communication and stress, in that Leventhal and colleagues used these initial results to develop an explanation of how people perceive illness as a threat.

There are two main features of this model; the independent processing of cognitive representations of a danger (e.g. a disease threat) and of fear; and the distinction of the representations of the disease from the plan or procedures for performing a protective response (i.e. coping response). External and internal stimuli (such as symptoms) activate cognitive illness representations in memory, and form a coherent representation of the current condition. These representations then activate
coping responses to deal with the threat, which are then appraised for their efficacy in dealing with the threat of illness. At the same time, the stimuli also activate emotional representations, which simultaneously lead to the adoption of strategies to deal with the emotional response to the threatening stimuli.

The processing of both emotional and cognitive responses simultaneously has led to the model being described as a parallel processing model, whereby communication of a threat, (be it illness risk information or a confirmed diagnosis), motivates an individual to engage in danger control, and fear control. Danger control is defined as the influence of information from the external environment and one’s coping behaviours on the decision to act and engage in coping responses. Fear control encompasses emotional information and its influence on choosing actions to minimise the emotional response. The authors suggest that although there are interactions between both fear and danger control, they are separate components that can lead to different responses. This exemplifies how Leventhal first proposed the ways in which parallel processes affect persuasion and fear. When participants are exposed to a mild fear message regarding dental practice, for example, they are motivated to control danger and respond to this message by changing their dental health practices. In contrast, when exposed to a high fear message, participants will seek to control their fear, rather than control the danger (Janis & Feshbach, 1953).

**Illness Perceptions**

Individuals seek information to assess the meaning of their symptoms and physical state, and the relevance of these towards previous experiences. The cognitions formulated from this information create a coherent pattern or understanding of illness that directs a person’s behaviour in goal-directed ways. These perceptions (also known as illness beliefs, cognitions, representations) can be constructed from a wide variety of sources, such as social and cultural information; the media; education; as well as personal and family experiences of illness. Non-adherence to treatment regimens or health care practices may stem from the fact that participants may develop their own perceptions of danger, and although their behaviour may be congruent with their own beliefs, they are not in line with recommended actions. For example, a smoker may not give up smoking, but instead switch to a low tar or filtered brand of cigarettes to reduce their risk of lung cancer.
(Leventhal & Cleary, 1980). For this reason, Leventhal and colleagues (Leventhal et al., 1970) argue that it is crucial to examine the individual perceptions of illness threat in people, to understand how people construct perceptions, and consequently, how they influence behavioural coping. The function of illness perceptions is to develop action plans to minimise the illness threat. In this way, perceptions can be used to monitor the threat over time, and adjust coping responses accordingly.

According to Leventhal and colleagues (Leventhal et al., 1980), illness perceptions include both concrete and abstract information. Representations of illness threats can be both perceptual (e.g. symptoms), and conceptual (e.g. labels of an illness). For example, the symptoms of heart disease would lead to the identification of heart disease as the label for the symptoms (conceptual), whilst also guiding medication usage to treat heart disease (perceptual). Meyer, Leventhal, and Gutmann (1985) examined the use of perceptual and conceptual codes. They asked patients with hypertension whether they were able to tell when they were hypertensive, despite it being an asymptomatic disease. For patients new to treatment, 71% believed they could tell, whereas 94% of patients who had returned for treatment after being non-adherent for some time, believed they could tell through monitoring of their symptoms. In fact, the presence of symptoms in this group acted as a cue for returning to treatment for hypertension. Moreover, patients new to treatment were followed up six months later, and 92% reported being able to tell when hypertensive, based on symptom monitoring.

Research such as this led to the hypothesis that perceptual and conceptual codes lead to a drive for symmetry. According to this symmetry rule, patients will always actively seek and assign meaning to somatic events, and given a label, people will seek somatic sensations or symptoms (Leventhal et al., 1997). Although hypertension is a condition which cannot be monitored through outward symptoms, patients’ conceptual codes can drive them to believe that their perceptual codes are related. People search for a label or name when feeling unwell, and when told that they have an illness, people expect to feel ill. Informing participants that they have a disease can lead to increased symptom reporting (e.g. Baumann, Cameron, Zimmerman, & Leventhal, 1989). In this way, the symmetry rule can affect adherence to medication; if the labels and symptoms are not congruent, medication or treatment may not be deemed necessary.
According to Diefenbach and Leventhal (1996), patients also make causal attributions of their symptoms. One particular attribution that has garnered some attention is stress. Somatic sensations are more likely to be seen as being related to stress if the person is experiencing stressful events. For example, Cameron and colleagues (Cameron, Leventhal, & Leventhal, 1995) asked 366 people in the general population to report symptoms, life stressors, and healthcare-seeking behaviour over five interviews. The researchers noted that when a symptom was identified as ambiguous and occurred during a time of stress, it was more likely to be attributed to stress.

Baumann, Cameron, Zimmerman, and Leventhal (1989) asked 251 students to rate the likelihood of a set of symptoms being caused by stress or by an illness if they were to experience them the following day. The sets of symptoms were ambiguous, or representative of either diabetes or mononucleosis. Students were asked to rate the sets of symptoms either the day before an examination, or before a weekend associated with no stressful event. Results indicate that students were more likely to rate the ambiguous and diabetes symptom sets as related to stress the day before an exam. These studies provide evidence for what Leventhal and Diefenbach (1991) term the stress-illness rule. Symptoms experienced during times of stress will be attributed to stress, whilst symptoms experienced in the absence of stress are more likely to be attributed to medical causes (Diefenbach & Leventhal, 1996).

People will also make a decision about whether their sensations are due to illness, or simply normal signs of ageing. The ageing process does involve a number of physical changes, and some signs of illness may be misattributed to ageing. This finding led to the formulation of the ageing-illness rule. Familiar and gradual onset symptoms are more likely to be attributed to ageing, whilst novel, unfamiliar symptoms that occur suddenly are less likely to be attributed to ageing (Prohaska, Keller, Leventhal & Leventhal, 1987).

In their early work on cognitions, Leventhal and Diefenbach (1991) identified these three rules or questions that people use to identify and make sense of their illness and symptoms. The symmetry rule involves the identification and labelling of symptoms as an illness; in contrast, the stress-illness and age-illness rules both relate more to causal attributions of an illness. These perceptions interact to form a coherent conceptualisation of the symptoms experienced. Leventhal and Diefenbach acknowledge that there may be more than three rules that can influence
the development of illness perceptions, coping actions and appraisals, but that these three rules are the most evident in their findings.

**Structure of illness perceptions**

Leventhal and colleagues (Leventhal et al., 1980) used semi-structured interviews to elicit both patients’ illness experiences and perceptions of illness. From the original interviews, the researchers were able to ascertain that illness perceptions can be categorised into distinct dimensions. Research findings related to the symmetry rule identified symptom identity as the first dimension to be confirmed. Other researchers conducted open-ended interviews with a wide variety of illnesses, and further identified consequences, causes and timeline as additional dimensions. Lau and Hartman (1983) interviewed 320 undergraduate students about recent illnesses they had experienced. They found that participants discussed perceptions of consequences, timeline, and identity, as well as perceptions of curability and control. Lau and Hartman suggested that this dimension was not considered in previous literature because of the focus on severe illness, where there is very little chance of cure, and limited opportunities for control, so a fifth dimension labelled control/cure was confirmed.

Scharloo and Kaptein (1997) conducted a review of studies that assessed illness perceptions in some form between 1985 and 1995. The majority of studies focused on chronic pain patients, and all examined chronic illnesses. Twenty studies measured illness perceptions using semi-structured or open-ended interviews; not all dimensions proposed by Leventhal and colleagues were studied. Instead the majority focused on control beliefs (59 studies), causal attributions (44 studies), or consequences (39 studies), using a wide variety of methodologies. Timeline and identity were also measured in a number of studies, but were less commonly examined. Although some of the studies included in the review utilised different underlying models, they all showed some evidence for a five-component model of illness perceptions (Scharloo & Kaptein, 1997). The five dimensions commonly associated with the model are identity, consequences, cure/control, timeline, and causes. According to the model, these five dimensions have unique characteristics, but form a coherent and consistent view of illness (Petrie & Pennebaker, 2004).
Identity is related to both the label and the associated symptoms of the illness. According to Bishop and Converse (1986), identity beliefs are prototypical in nature. People hold a typical or representative scenario of an illness, and compare their own situation to that prototype. In these terms, the prototype of a myocardial infarction (MI) would include intense chest pain; whereas other symptoms, such as indigestion and fatigue, may not be included, as they are seen as less typical of the condition. Consequence beliefs relate to the perceived impact or severity of an illness; both in social, physical, emotional, and economic terms. The consequences can be perceived as either negative or positive, and can include both short and long-term consequences.

The cure/control dimension relates to beliefs regarding how curable or controllable an illness is. It includes beliefs about what can be done to exert an influence on the course of an illness, both in terms of personal control, what others such as healthcare professionals can do to cure the illness, and the ability of treatment to control or cure the disease.

Timeline beliefs relate to the perceived timeframe or duration of an illness. Interviews conducted with patients to elicit their illness experiences showed that people hold at a basic level, three types of disease models that identify the disease according to its timeline (Diefenbach & Leventhal, 1996). The first relates to an acute illness (e.g. influenza, gastrointestinal upset); the second is for cyclic ‘flare-ups’ (e.g. allergies, psoriasis); and the third is for a chronic disease (cancer, heart disease, arthritis).

Causes relates to the perceptions of what likely caused the illness. According to Weiner’s theory of causal attributions (Weiner, 1986), attributions can be distinguished based on three factors: causality, stability, and controllability. Causal beliefs vary considerably, but are often ordered into dimensions related to biological, emotional, psychological and environmental causes.

These dimensions were developed from extensive interviews, and the five dimensions are considered to be the basic template that people use to represent an illness (Heijmans & deRidder, 1998). Evidence for the consistency and validity of the components has been seen in a number of studies (Skelton & Croyle, 1991). For example, in a meta-analysis by Hagger and Orbell (2003), 45 studies testing Leventhal’s Self-Regulatory Model (SRM) across 23 conditions were assessed. The five dimensions were confirmed, with good reliability and validity found for each of
these dimensions (Hagger & Orbell, 2003; Weinman, Petrie, Moss-Morris, & Horne, 1996).

**Measurement of illness perceptions**

The original methods employed to elicit perceptions of illness were time-consuming, and led to huge variation across patient responses. Questionnaires were developed to provide a standardised way of comparing dimensions across patient samples. One of the first questionnaires used to assess beliefs was developed by Prohaska, Leventhal, Leventhal, and Keller (1985); however, this measure was limited in its ability to measure all the dimensions of the model, so has been seldom used in research since its development.

The Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne, 1996) was the first measure specifically developed to assess all five dimensions of the model. This questionnaire has five subscales: identity, timeline, cure/control, consequences and causes. The measure is quite flexible in that the items can be generic (‘my illness’), or tailored to specific populations, such as ‘my diabetes’, or ‘my asthma’. The measure also allows for use in healthy populations, spouses of patients, or to conduct comparative assessments of illness perceptions across a range of different conditions. In its development, it was compared to the interview schedule utilised by Leventhal and Nerenz (1985), and found to be consistent with the original dimensions. The measure was assessed across seven illness groups, and showed good internal consistency and test-retest reliability, as well as concurrent, discriminant and predictive validity (Weinman et al., 1996).

Since its development, the IPQ has shown good reliability and validity in a wide range of illness populations, such as patients with cancer (Anagnostopoulos & Spanea, 2005; Buick, 1997), heart disease (Petrie, Weinman, Sharpe, & Buckley, 1996), rheumatoid arthritis (Murphy, Dickens, Creed, & Bernstein, 1999), and diabetes (Griva, Myers, & Stanton, 2000).

Not all researchers have adopted the five dimensions. For example, the Implicit Models of Illness Questionnaire (IMIQ; Turk, Rudy, & Salovey, 1986) was developed originally with a sample of people with diabetes, students, and diabetes educators. Factor analyses revealed that the IMIQ has four dimensions; seriousness, personal responsibility, controllability, and changeability. Schiaffino and Cea (1995)
examined the factor structure of this measure in students, and patients with multiple sclerosis, rheumatoid arthritis or HIV. Factor analyses also revealed a four factor structure of illness perceptions, but these factors were different to those originally proposed by Turk and colleagues (1986). The dimensions found by Schiaffino and Cea included curability, personal responsibility, symptom variability, and serious consequences. These factors loosely map onto the original dimensions proposed by the model (Leventhal, Meyer, & Nerenz, 1980).

Measures have also been developed for use with specific samples, such as the Personal Models of Diabetes Interview (PMDI; Hampson, Glasgow, & Toobert, 1990), or the Diabetes Illness Representations Questionnaire (Skinner et al., 2003). These measures have been used to successfully elicit illness perceptions in patients with diabetes. The difficulty in these measures; however, is that their use is restricted to patients with diabetes, and does not utilise the five dimensions identified. These measures therefore cannot facilitate comparison across diseases, and the advancement of our understanding of the model.

Although the model has received support for the five dimensions, Leventhal and colleagues note that each of the five dimensions can be further differentiated. For example, the causal subscale can be categorised into environmental, psychological, and biological causes. Similarly, perceptions of control may differ based on personal or disease-related control (Thompson, 1991). These distinctions cannot be made when measuring illness perceptions using the IPQ. For this reason, the Revised Illness Perception Questionnaire was developed (IPQ-R; Moss-Morris et al., 2002).

The IPQ-R was built upon the five component structure used in the IPQ, but sought to address the limitations evident in the original questionnaire. Both the control and timeline subscales displayed much lower internal consistency than the other dimensions in the IPQ. In addition, factor analyses illustrated that control loaded onto two factors; personal control beliefs and outcome expectancies for treatment. The original timeline subscale categorised patients as acute or chronic, with a notable absence of measurement of cyclical timeline beliefs. The control dimension was therefore further divided into personal and treatment control; and timeline was divided into acute/chronic and cyclical timeline.

Two additional subscales were included: emotional representations and illness coherence. The emotional representations subscale was developed to address
the exclusion of the emotional processes of the model in the original questionnaire. Emotional representations are an important part of the SRM, but were traditionally excluded from its measurement. Illness coherence was also included as a measure of the level of comprehension or understanding that patients have about their illness. Illness coherence can be conceptualised as a meta-cognition that encompasses the way in which patients think about and understand their illness as a whole (Moss-Morris et al., 2002).

The identity subscale in the IPQ may measure level of symptom reporting, rather than illness identity, in that it asks participants to rate the extent to which they experience the symptoms listed (Moss-Morris et al., 2002). The IPQ-R identity subscale instructions were modified so that participants are instead asked to state what symptoms (from a given list) are related to their illness. There were also some noted difficulties with the causal subscale, with anxiety and depression being part of both emotional and psychological causal attributions. This stems from a variety of ways in which causal beliefs have been measured, which leads to difficulty in interpretation across studies and illnesses. To address this problem, researchers argue for the use of factor analysis on the causal items, so that the dimensions developed are meaningful. In addition, the inclusion of illness-specific causal items is considered to improve the meaning of these perceptions (Moss-Morris et al., 2002). For these reasons, eight further items developed from specific illness research using the IPQ were included in the causal subscale (Moss-Morris & Petrie, 2001; Petrie et al., 1996; Pimm & Weinman, 1998).

Eight illness groups were utilised to develop the IPQ-R, and it demonstrated good reliability in both the original and newly developed subscales. In particular, illness coherence was considered useful in that it provides a score for how a patient makes overall sense of their illness. The measure has also been confirmed for its reliability and factor structure in a number of studies, across various samples such as patients with diabetes (Skinner et al., 2011) and adults with cystic fibrosis (Sawicki, Sellers, & Robinson, 2011). In addition, confirmatory factor analyses confirm the general acceptability of the IPQ-R as a measure for colposcopy patients (Hagger & Orbell, 2005), women with breast cancer (Giannousi, Manaras, Georgoulias, & Samonis, 2010; Rozema, Völlink, & Lechner, 2008), and patients with oesophageal cancer (Dempster & McCorry, 2012), although some variations are apparent in the consistency of the subscales.
Due to their good reliability and consistency, the IPQ and IPQ-R are the most common measures used to assess illness perceptions. For example, 60% of all studies reviewed by Hagger and Orbell (2003) used these measures either in their original or adapted form. A brief version of the IPQ has also been developed (The Brief Illness Perception Questionnaire; BIPQ; Broadbent, Petrie, Main, & Weinman, 2006), to aid in the rapid measurement of illness perceptions in clinic-based settings, and where repeated measurements are required across numerous time points.

Although measures that include close-ended questions allow for greater comparison across illnesses and studies and greater standardisation, Diefenbach and Leventhal (1996) acknowledge the utility of open-ended questions to give participants the opportunity to elaborate on their representations, and to include aspects that are not included in the standardised measures. In this way, alternate methods for eliciting illness perceptions have been developed. Broadbent, Petrie, Ellis, Ying, and Gamble (2004) assessed illness perceptions of MI in 74 patients through freehand drawings of their hearts after an MI. The drawings highlighted the huge amount of variance in patients beliefs regarding the extent of damage sustained. The level of damage depicted in the drawings related to subsequent rates of return to work and later perceptions of recovery. This method of eliciting illness perceptions is considered beneficial, in that drawings of damage not only illustrate cognitions, but also the level of emotional responses to the condition. In a follow-up study, Broadbent, Ellis, Gamble, and Petrie (2006) measured the size of the heart drawings in 79 cardiac patients. They found that patients who drew much larger drawings of their heart reported more cardiac anxiety, slower return to work, perceived greater risk of future MI, and greater healthcare utilisation.

Harrow and colleagues (Harrow, Wells, Humphris, Taylor, & Williams, 2008) conducted a qualitative study asking women to describe their breast cancer tumour. Women either identified their tumour as creature-like, such as a jellyfish; or as a substance, such as a hard lump. Those who described their tumour as a creature were more distressed and reported more intrusive thoughts. The results indicate that the use of imagery can be developed to effectively measure illness perceptions in populations that are not currently possible. For example, the use of drawings and imagery can elicit perceptions of illness in young children, and in those who experience literacy or language comprehension problems that preclude them from participating in traditional research.
Patterns of illness perceptions

Leventhal, Meyer, and Nerenz (1980), note that due to the factorial methods utilized to explain the five factors, it may appear that the factors are clustered. He contends however, that they are instead organised into sets, and that there will be distinct patterns of illness representations for different diseases according to symptoms and chronicity. For example, the three types of disease models (acute, cyclical and chronic) may hold specific patterns of identity, causes, timeline, control and consequences. For example, those who label their illness as acute would also have high control/cure beliefs, but less serious consequences. In contrast, holding a chronic illness belief would be related to serious consequences and low levels of control or cure (Petrie & Pennebaker, 2004).

A meta-analysis of 45 studies utilising the five-component model (Hagger & Orbell, 2003) was conducted to assess illness perceptions and their relationship to one another. Correlational analyses revealed a consistent pattern of results between constructs, with cure/control negatively related to consequences, identity, and timeline; whilst consequences, identity and timeline were all positively correlated (Hagger & Orbell, 2003). This suggests that people who hold a strong illness identity would also believe that their illness was less controllable, more chronic, and have a more serious impact. Similarly, people who hold strong control beliefs also tend to hold less serious consequences and chronicity beliefs.

These correlations suggest that although independent constructs, people tend to report perceptions as clustered in consistent patterns. These findings have been confirmed in more recent studies (e.g. McCory et al., 2012; Rozema et al., 2008; Vaughan, Morrison, & Miller, 2003), suggesting that there are patterns of illness beliefs that provide evidence for ways in which patients organise information about their illness. These findings support the construct validity of the dimensions, while also providing evidence for the continued use of measures such as the IPQ-R to elicit the dimensions. When these measures are adapted for specific illnesses (e.g. PMDI; Hampson et al., 1990), the results still tend to cluster around the same dimensions.

Another way that illness perceptions have been examined in terms of clusters, or sets, has been whether illness perceptions are distinguishable across conditions. Schiaffino and Cea (1995) compared the illness perceptions of people with rheumatoid arthritis (RA), multiple sclerosis (MS), and HIV, to students’ ratings of
all three illnesses using the IMIQ. They found that RA was rated as more curable, variable, and patients were considered less to blame for their condition by students; whilst people with HIV were considered to be the more responsible for their illness. Students rated MS as far more serious than RA and HIV, and even rated the illness as more serious than patients with MS rated themselves. Similarly, Moss-Morris and Chalder (2003) examined illness perceptions in 49 patients with chronic fatigue syndrome and 74 patients with rheumatoid arthritis. Results indicate that patients with chronic fatigue syndrome report stronger illness identity, more serious consequences, and are more likely to attribute the cause of their condition to a germ or virus.

**Illness Perceptions and Coping**

Illness perceptions guide the response to an illness, and this is often defined in terms of coping strategies or coping behaviours. Coping can be classified within three levels (Skinner, Edge, Altman, & Sherwood, 2003). The lowest level includes instances of coping, such as taking medication or reading an information leaflet. Intermediate coping classifies these instances of coping into particular strategies such as denial or problem solving. The highest order of coping further defines these strategies into types of adaptive processes, such as problem-focused and emotion-focused coping (Lazarus & Folkman, 1984). Problem-focused coping includes engaging in strategies that are directly focused at a particular problem, and include strategies such as seeking information, and problem solving. Emotion-focused coping includes cognitive strategies to manage emotional distress, and includes avoidance, distraction and reappraisal (Lazarus & Folkman, 1984).

The model proposes specific links between cognitions and coping; however, this link is not always examined in the literature. Of those studies that have measured both coping and illness perceptions, positive relationships have been shown. In their meta-analysis, Hagger and Orbell (2003) found that the cure/control dimension is positively related to problem-focused coping, whilst the other dimensions are related to avoidance and denial (Hagger & Orbell, 2003). Expressing emotions, avoidance, and denial is correlated with severe consequences and a strong illness identity. Control/cure is also related to cognitive reappraisal, problem solving and seeking social support. Maladaptive coping strategies are correlated with severe
consequences, chronic timeline and strong illness identity, and negatively correlated with adaptive coping (Hagger & Orbell, 2003).

These results have been confirmed in a number of studies. Patients who believe that their illness is uncontrollable tend to engage in more passive coping (Moss-Morris, Petrie, & Weinman, 1996). Similarly, beliefs of internal, unstable, controllable causes are associated with emotion-focused coping (Roesch & Weiner, 2001). Moss-Morris and colleagues (Moss-Morris et al., 1996) noted that in people with chronic fatigue syndrome, identity, cure/control, and consequences were related to behavioural disengagement, whilst identity and cure/control were also related to active coping and seeking social support. Similarly, Kemp, Morley, and Anderson (1999) found that perceived control was related to problem-focused coping. In contrast, severe consequence beliefs and a strong illness identity were related to avoidance and wishful thinking.

Llewellyn, McGurk, and Weinman (2007) examined illness perceptions in people with head and neck cancer, and found that identity was related to distraction and venting emotions, whereas chronic timeline beliefs were related to long-term planning. Similarly, severe consequences were related to venting, and those who reported negative emotional representations had higher levels of coping by denial and substance use. Interestingly, these associations were strongest at 6-8 months follow-up, indicating that pre-treatment beliefs are important for coping over time.

Buick (1997) found that a strong illness identity, severe consequences, chronic timeline and low control were related to venting emotions, disengagement and less coping flexibility 3 months post-treatment for breast cancer. Moreover, Rozema, Völlink, and Lechner (2008) also found positive associations between illness perceptions and coping in 119 women with breast cancer. Problem-focused coping was related to a lower belief in a psychological cause of cancer, and higher personal control; whilst venting emotions was also related to negative emotional representations.

**Illness Perceptions and Psychological Outcomes**

The SRM asserts that peoples’ behaviour is directed by goals, and understanding these goals allows us to understand behaviour (Marteau & Weinman, 2006). Illness perceptions not only guide coping, they also directly influence health-
related behaviour (Leventhal et al., 1980), and evaluations of treatment (Horne & Weinman, 1999; 2002). Illness perceptions have been examined in a number of acute and chronic illnesses, and found to influence a wide variety of outcomes (Hagger & Orbell, 2003). Consistent with the model, consequences, identity and timeline were negatively associated with psychological well-being, social and role functioning, and vitality, but positively associated with psychological distress. Consequences and identity also displayed a negative relationship with physical functioning (Hagger & Orbell, 2003). These findings suggest that patients who hold strong negative beliefs as to the consequences of their illness, a chronic timeline, and a strong illness identity tend to report more negative illness outcomes. Many studies have been conducted across a wide range of illnesses to determine the efficacy of illness perceptions in predicting health-related outcomes and distress.

Cure / Control

Control has been researched as a predictor of adjustment for many years, and having a sense of personal control has consistently been shown to be predictor of more positive health-related outcomes (Stiegelis et al., 2003; Taylor, Lichtman, & Wood, 1984; Thompson & Collins, 1995). Low control beliefs are related to higher depression and anxiety levels in patients with rheumatoid arthritis (Groarke, Curtis, Coughlan, & Gsel, 2004; 2005), and cystic fibrosis (Sawicki et al., 2011). Perceived cure accounted for between 5-25% of the variance in well-being when demographic and disease variables were controlled in patients with Huntington’s disease (Helder et al., 2002). Vaughan, Morrison, and Miller (2003) examined illness perceptions and their relation to health outcomes in people with multiple sclerosis (MS). Holding high levels of cure/control were related to better physical functioning and lower levels of depression. Similarly, a strong belief in personal control was related to less anxiety and depression, as well as less physical fatigue, but more mental fatigue in patients with MS (Jopson & Moss-Morris, 2003).

Low perceived control over both symptoms and emotional reactions to cancer can predict greater levels of distress (Thompson, Sobolew-Shubin, Galbraith, Schwankovsky, & Cruzen, 1993). Carver and colleagues (Carver et al., 2000), found that women with high personal control beliefs were more optimistic about breast cancer recurrence than those who held more externally-based control beliefs. In
contrast, others have noted that perceptions of control of cancer recurrence were not related to distress at diagnosis or at follow-up (Malcarne, Compas, Epping-Jordan, & Howell, 1995).

It has been noted; however, that distinctions between control over the consequences of a disease, and the disease itself, are important in illustrating its exact influence. In situations of low objective control, patients may concentrate on aspects of a situation in which they can exert some control, such as the management of symptoms (Carver et al., 2000; Lev, Paul, & Owen, 1999). In this way, it is more adaptive for patients to hold a strong sense of personal control over daily actions and emotions, rather than being able to control the disease course itself (Thompson, 1991). Tomich and Helgeson (2004) reported that perceived control over day-to-day symptoms was related to better functioning and less distress in women with breast cancer. In people with rheumatoid arthritis (Schiaffino, Shawaryn, & Blum, 1998), having a strong sense of cure and personal responsibility predicted higher levels of depression. Similarly, in those experiencing severe cardiac symptoms, perceived internal control was related to better medical, psychological and behavioural indices, whereas beliefs in personal control over the illness course was related to more negative outcomes (Affleck, Tennen, Croog, & Levine, 1987; Affleck, Tennen, Pfeiffer, & Fifield, 1987). These results highlight the importance of clear definitions of perceived control, as well as the potential contrasting influence of control on distress.

**Causes**

Causal beliefs have also displayed the ability to determine distress and psychological functioning. For example, Schiaffino and Revenson (1995) examined patients with rheumatoid arthritis, and found that patients who held internal, stable causal attributions, reported more disability. Causal beliefs are also often highly related to emotional responses, especially if patients attribute the cause of their illness to personal behaviours such as smoking and eating habits (Petrie & Pennebaker, 2004). Believing oneself to blame can also lead to poorer emotional outcomes in patients with cancer (Newsom, Knapp & Schulz, 1996).

Fortune, Richards, Griffiths, and Main (2002) examined the utility of illness perceptions and coping in predicting distress and disability in psoriasis sufferers. A
strong belief in an emotional cause helped to explain 28% of the variance in anxiety, 43% of depression, and 31% of the variance in worry. Holding a belief that inflammatory bowel disease (IBD) is caused by psychological causes was related to higher levels of depression (Dorrian, Dempster, & Adair, 2009). Similarly, Rutter and Rutter (2002) reported that holding higher emotional causal beliefs leads to more anxiety in people with irritable bowel syndrome.

Consequences
Beliefs in serious consequences are consistently related to poorer health-related outcomes. This has been shown in people with multiple sclerosis (Schiaffino & Cea, 1995; Schiaffino et al., 1998; Vaughan et al., 2003), rheumatoid arthritis (Groarke et al., 2005; Sharpe, Sensky, & Allard, 2001), chronic fatigue syndrome (Heijmans, 1998), and irritable bowel syndrome (Rutter & Rutter, 2002). Moreover, perceived negative consequences predicted 28% of the variance in disability in people with psoriasis (Fortune, Richards, Griffiths, & Main, 2002).

Sawicki, Sellers and Robinson (2011) examined the utility of illness perceptions in explaining health outcomes in patients with cystic fibrosis. One hundred and ninety nine patients completed measures of health functioning and illness perceptions. Analyses revealed that severe consequences beliefs were related to lower scores in body image, health perceptions, and emotional social and role functioning. Additionally, Jopson and Moss-Morris (2003) examined 168 people with MS, and found that a belief in serious consequences was the most significant predictor of distress.

Identity, timeline, and illness coherence
For a number of studies, identity has explained the most variance in illness outcomes in comparison to the other dimensions (Kemp, Morley, & Anderson, 1999; Scharloo et al., 1998). Holding a strong illness identity predicted higher levels of anxiety and depression in 99 individuals with multiple sclerosis (Vaughan, Morrison, & Miller, 2003). In people with Huntington’s disease, identity accounted for 28% of the variance in psychosocial functioning (Helder et al., 2002), and also contributed to poorer physical functioning (Kaptein et al., 2006). A strong illness identity also
predicted greater anxiety, depression, and worry, whilst consequences and identity also accounted for 54% of the variance in levels of daily hassles in 225 psoriasis sufferers (Fortune et al., 2002).

Although timeline is considered one of the main five illness perceptions, its ability to predict health-related outcomes is less apparent. Very few studies have shown that timeline is a significant predictor of psychological and physical functioning. Holding an acute timeline belief was predictive of a faster return to work in patients with cardiovascular disease (Petrie et al., 1996). In contrast, holding a more chronic timeline belief predicts more negative health outcomes at 12 and 24 months in patients attending primary care (Frostholm et al., 2007).

There are only a small number of studies that have assessed illness coherence for its predictive ability on health-related outcomes, as it was not a part of the original IPQ (Weinman et al., 1996). The influence of illness coherence on outcomes and distress is inconsistent, with Skinner and colleagues (Skinner et al., 2011) noting that high levels of illness coherence were more predictive of depression in 564 patients with diabetes. In contrast, reporting a high level of illness coherence was associated with better emotional and social functioning scores in 199 patients with cystic fibrosis (Sawicki et al., 2011). The disparities in the results may stem from the differences in analyses conducted; illness coherence was assessed as a separate construct in the study by Sawicki and colleagues (2011), but as part of a grouping of illness perceptions through the use of cluster analysis in the study by Skinner and colleagues (2011).

Scharloo and Kaptein (1997) noted that out of 14 studies, numerous associations were found between health outcomes and illness perceptions. In particular, perceived control and consequences seem to have more of an influence on health outcomes. Kaptein and colleagues (Kaptein et al., 2003) conducted a review of five chronic illnesses and assessed the impact of illness perceptions on health outcomes. This review only assessed a very limited number of studies, not all of which explicitly measured the five dimensions as proposed by Leventhal’s model. Despite these limitations, some general conclusions can be made. For example, identity and consequences are related to medication adherence in asthma (Horne & Weinman, 2002), but are related to well-being and functional status in people with chronic obstructive pulmonary disease (Scharloo, Kaptein, Weinman, Willems, & Roojmans, 2000). Identity and timeline are associated with depression and well-
being in patients with neurological disorders (Helder et al., 2002; Schiaffino, Shawaryn, & Blum, 1998). Identity is also important in cancer patients (Bradley, Calvert, Pitts, & Redman, 2001), whilst timeline, control, causes and consequences are all related to health outcomes in patients with cardiovascular disease (Petrie et al., 1996).

**Prospective findings**

Although the evidence is promising regarding the influence of illness perceptions on health outcomes, an over-reliance on cross-sectional and correlational data is a limitation in the literature. It is therefore difficult to ascertain the direct influence of illness perceptions to health outcomes. Frostholm and colleagues (Frostholm et al., 2007) assessed illness perceptions in patients attending their GP for new or recurrent symptoms, and examined their influence to health outcomes over a two year period. The authors asked 1785 patients attending their GP to complete the IPQ and a measure of quality of life at baseline, 3, 12 and 24 months follow-up. The researchers found, in confirmation of previous research, that negative illness perceptions were associated with poorer mental and physical health outcomes at baseline. Importantly, they also found that a chronic timeline, serious consequences and negative emotional representations of their illness combined to predict more negative health outcomes at 12 and 24 months. Independently from the other dimensions, a strong illness identity appeared to predict poorer health outcomes at each time point.

Juergens, Seekatz, Moosdorf, Petrie, and Rief (2010) assessed the ability of illness beliefs to predict quality of life in 56 patients three months after undergoing cardiac surgery. A strong illness identity, a chronic or cyclical timeline belief and serious consequences explained 22% of the variance in illness-related disability. Beliefs in less serious consequences and a more acute timeline explained 12% of the variance in physical functioning. Low levels of coherence, a chronic timeline and severe consequences predicted 14% of the variance in depression at three month follow-up. In contrast, psychological well-being was not related to any illness perceptions. Although the amount of variance explained was modest, illness beliefs were stronger predictors of the health outcomes than disease and demographic variables.
Skinner and colleagues (Skinner et al., 2011) conducted cluster analysis on their prospective data of 564 patients with type 2 diabetes and recorded four distinct clusters, (acceptors, acceptors resisting, resistors, resistors accepting). Results indicated that acceptors reported less depression at 4 and 12 month follow-up. This is in line with previous studies that indicate that holding more positive illness perceptions predicts better outcomes.

Not all studies have found significant results regarding illness perceptions over time; however. Groarke, Curtis, Coughlan, and Gsel (2005) examined illness perceptions in 52 patients with rheumatoid arthritis over a two year period. After controlling for demographic and disease variables, cross-sectional analyses revealed that at one year follow-up, low perceived control predicted greater depression and anxiety, whilst two years later, cross-sectional analyses revealed more negative consequences predicted greater anxiety and depression. Despite this, longitudinal analyses revealed that illness perceptions did not explain any of the variance when baseline levels of adjustment were controlled.

**Illness Perceptions, Coping, and Psychological Outcomes**

The Self-Regulatory model contends that the influence of illness perceptions on health-related outcomes and distress occurs through the influence of coping; coping acts as a mediator between illness perceptions and psychological outcomes. Despite a number of studies examining this relationship in a wide variety of conditions (Scharloo, et al., 1998), such as inflammatory bowel disease (Dorrian et al., 2009), Huntington’s disease (Kaptein et al., 2006), chronic fatigue syndrome (Heijmans, 1998), and breast cancer (McCorry et al., 2012; Rozema et al., 2008), only a small number of studies have found evidence for the mediating role of coping. For example, Rutter and Rutter (2002) conducted path analyses on 209 patients with irritable bowel syndrome and found that the influence of cure/control on satisfaction with health was mediated by active coping. The relationship of consequences to depression was fully mediated by behavioural disengagement, and partially mediated by restraint coping. Acceptance mediated the effect of the consequences on quality of life, whilst the relationship of psychological causes and serious consequences to anxiety was mediated by venting of emotions. Similarly, Gould, Brown, and Bramwell (2010) assessed illness perceptions and coping in 61 women to
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gynaecological cancer. Analyses revealed that the relationship between cyclical timeline and illness coherence with negative mood was mediated by denial and avoidant coping.

Coping appraisal and psychological outcomes

Illness perceptions guide response to illness via coping, but individuals also engage in appraisals of the efficacy of coping strategies employed. According to the model, the perceived efficacy of the persons coping with an illness threat is evaluated, which then further influences behavioural and emotional responses. For example, if the coping efforts are considered to be ineffective in responding to an illness threat, then distress levels may increase (Love et al., 1989; Nerenz, Leventhal, & Love, 1982). This highlights the cyclical nature of the model, in that illness perceptions guide coping, distress and behaviour, whilst coping appraisal can determine illness perceptions and coping efforts, leading to changes in distress and behaviour (see Figure 1).

Keefe and colleagues (Keefe et al., 1997) examined coping appraisal in people with rheumatoid arthritis, using two items, and noted that greater reported coping appraisal in dealing with pain led to improved mood and better coping with pain the following day. Additionally, Katz (1998) discovered that perceived coping appraisal was related to higher levels of medication usage. Wang, Badley and Gignac (2004) examined coping and coping appraisal in 286 people with osteoarthritis or osteoporosis. Coping appraisal, measured by three items, mediated the relationship between activity limitation and self-perceived independence to personal care and mobility.

Hulbert-Williams, Neal, Morrison, Hood, and Wilkinson (2011) assessed coping appraisal with eight appraisal statements adapted from Smith and Lazarus (1993), in 160 patients with cancer. They found that coping appraisals were more predictive of anxiety and depression than coping. Moreover, lower coping appraisal predicted greater fear of recurrence in 155 women with breast cancer, although the variance explained was small (McGinty, Goldenberg, & Jacobsen, 2012). Similarly, Gallagher, Parle and Cairns (2002) assessed coping appraisal in 195 women with breast cancer. Women with lower threat appraisals and higher coping appraisals reported greater psychological functioning 6 months after diagnosis. No study to date
has assessed illness perceptions, coping, and coping appraisal in the same study, so much more work is needed to provide evidence for coping appraisal within the SRM framework.

Figure 1. The Self-Regulatory Model (SRM) of Illness Behaviour (adapted from Hagger & Orbell, 2003; Leventhal, Meyer, & Nerenz 1980).

**The Self-Regulatory Model and Cancer**

There has been some focus in the literature regarding how the SRM can explain distress and responses to cancer. According to the model, cancer patients are active seekers of illness information, and perceptions of cancer guide coping strategies used to deal with the diagnosis of cancer (Petrie, Broadbent, & Meechan, 2003). Despite this, only a limited number of studies have assessed the relationship of illness perceptions to cancer.

Keeling, Bambrough, and Simpson (2012) examined illness perceptions and coping in 74 people with low-grade brain tumours. Analyses revealed that illness identity predicted greater levels of depression, whilst venting, denial, disengagement and self-blame predicted greater anxiety and lower positive affect. Similarly, Scharloo and colleagues (Scharloo et al., 2005) examined illness perceptions in
patients with head and neck cancer. After controlling for comorbidity, a strong illness identity and older age accounted for 39% of the variance in poorer physical functioning. Age, identity and cyclical timeline explained 79% of the variance in role functioning, with better functioning in patients who were younger, perceived fewer symptoms and held a cyclical timeline belief. In addition, strong emotional representations and lower illness identity was related to better emotional functioning. Social functioning was predicted by fewer behavioural causal attributions and negative emotional representations.

Llewellyn, McGurk, and Weinman (2006) found that illness perceptions were correlated with quality of life in 50 patients with head and neck cancer. Holding a strong illness identity, and more acceptance and self-blame coping were related to poorer mental health and physical functioning. Chronic timeline beliefs were also predictive of lower levels of vitality and social functioning. Longitudinal data from this study (Llewellyn, McGurk, & Weinman, 2007) showed that chronic timeline beliefs, and self-blame and acceptance coping strategies predicted depression six to eight months after treatment, accounting for more than 49% of the variance. Higher levels of acceptance predicted 21% of the variance in quality of life.

Bradley, Calvert, Pitts, and Redman (2001) qualitatively examined the utility of illness perceptions in predicting fear of recurrence in gynaecological cancer. Although the interview methodology used was not that outlined in Leventhal’s early work, the authors did find that illness identity was an important predictor of levels of recurrence fears. Hagger and Orbell (2006) also examined illness perceptions and their relation to distress following an abnormal screening result for cervical or colorectal cancer. Overall, emotional distress was predicted by identity, severe consequences, belief in a psychological cause, and low illness coherence.

Giannousi and colleagues (Giannousi, Manaras, Georgoulas, & Samonis, 2010) assessed illness perceptions in 206 individuals receiving chemotherapy treatment for cancer. Differences were found between patients who were receiving chemotherapy for the first time, and those who had already received chemotherapy. In particular, individuals who had previously received chemotherapy reported more symptoms, more severe consequences, and a more chronic timeline. In addition, severe consequences beliefs and negative emotional representations predicted approximately 50% of depression levels.
The majority of these studies examining illness perceptions and health outcomes in cancer are cross-sectional, so their predictive value is somewhat limited. Studies that have employed more prospective designs indicate that beliefs in a chronic timeline predict depression in head and neck cancer 6 to 8 months after treatment (Llewellyn et al., 2007), whilst a greater awareness of symptoms and an acute timeline leads to greater psychological morbidity in women with breast cancer over the first year since diagnosis (Millar, Purushotham, McLatchie, George, & Murray, 2005).

**Illness perceptions and breast cancer**

A small number of studies have assessed illness perceptions and their relationship with breast cancer. For example, Carver and colleagues (Carver et al., 2000) assessed two samples of women with breast cancer for their perceptions of personal control and expectancy of future occurrence. Women who held expectancies of remaining cancer-free were less distressed, but the study was cross-sectional, and perceptions were assessed using a single item.

Rabin, Leventhal and Goodin (2004) used a single measure to examine perceptions of timeline in 69 women receiving chemotherapy for breast cancer before, during, and after completion of treatment. Results indicated that, when controlling for disease characteristics, patients who conceptualised their cancer as chronic or cyclical reported more anxiety, depression, and fear of recurrence. The authors also noted that distress was unrelated to objective medical status; confirming the assumption that illness perceptions are more important in determining distress than objective indicators of health and illness.

Lichtenstein Jørgensen and colleagues (Lichtenstein Jørgensen, Frederiksen, Boesen, Elsass, & Johansen, 2009) examined distress and illness perceptions in 177 women with breast cancer. After controlling for clinical and demographic variables, higher reported quality of life was predicted by less severe consequences, explaining 23% of the variance. In addition, higher general distress was predicted by a more negative emotional response and a stronger belief that stress or worry caused breast cancer. These dimensions also explained a similar amount of variance (22%).

Further research has been conducted to assess illness perceptions and distress specifically in breast cancer patients undergoing treatment. Perceived
consequences were found to be related to both anxiety and depression in 72 women undergoing chemotherapy for breast cancer (Thuné-Boyle, Myers, & Newman, 2006). In addition, perceived symptom severity was also related to higher levels of anxiety, whilst numbers of symptoms reported and attributed to illness were related to depression (Thuné-Boyle et al., 2006). In contrast to expected effects, cure beliefs were not related to distress.

Buick (1997) examined 78 women undergoing either chemotherapy or radiotherapy as treatment for breast cancer before commencement of treatment, to three months post-treatment. Regardless of treatment type, holding more negative perceptions predicted greater disturbance in psychosocial functioning, but distress was not measured. Specifically, participants who reported lower cure/control, high illness identity, self-blame causal attributions, severe consequences, and chronic timeline before treatment commenced reported much lower quality of life scores 3 months post-treatment. Women who reported causal attributions related to the self were more likely to engage in health behaviour change, such as diet and changes in workload.

Coping and breast cancer

Although a small number of studies have measured illness perceptions in women with breast cancer, coping has received much more attention in the literature. Many studies have found relationships between coping and distress in women with breast cancer (Danhauer, Crawford, Farmer, & Avis, 2009; Hack & Degner, 2004). Owen and colleagues (Owen et al., 2006) examined 71 cancer patients and discovered that emotional suppression was predictive of greater distress. Iwamitsu and colleagues (Iwamitsu et al., 2005) also reported that women who report greater emotional suppression report greater mood disturbance. In addition, helplessness/hopelessness, anxious preoccupation, and cognitive avoidance were related to greater distress in both newly diagnosed patients and long-term survivors (Boyes, Girgis, Zucca, & Lecathelinais, 2009; Wang, Tu, Liu, Yeh, & Hsu, 2012). In contrast, more active styles of coping predict better psychological outcomes (Heim, Valach, & Schaffner, 1997).

There is much discussion as to the most adaptive or maladaptive coping styles for breast cancer patients. The established literature contends that problem-focused
coping styles such as fighting spirit, active coping, and seeking social support are adaptive, whilst emotion-focused coping such as denial, behavioural disengagement, and avoidance are maladaptive (Stanton & Snider, 1993). For example, coping styles such as passive acceptance and resignation predict poorer outcomes such as distress (Hack & Degner, 2004). Carver and colleagues (1993) reported that less acceptance at pre-surgery predicted greater post-surgery distress in 59 women with breast cancer. Similarly, denial and behavioural engagement predicted greater distress at six months, while greater use of humour was predictive of less distress. Greater problem-focused coping and less emotion-focused coping predicted less anxiety and depression in 80 women with breast cancer (Epping-Jordan et al., 1999). These variables explained 68% of the variance. After controlling for baseline distress, less problem-focused coping and more emotion-focused coping was related to less distress at 6 months. Additionally, emotion-focused disengagement was the strongest predictor of distress at six months.

Karademas, Argyropoulou, and Karvelis (2007) conducted path analyses on 103 breast cancer patients, and found that holding a more positive outlook and engaging in positive appraisal led to fewer depressive symptoms. Similarly, engaging in more positive reappraisal during surgery predicted more positive mood in 60 women with breast cancer at both 3 and 12 month follow-up and increased post-traumatic growth at 12 months (Sears, Stanton & Danoff-Burg, 2003).

Thuné-Boyle and colleagues (2012) conducted a cross-sectional study examining 108 breast cancer patients. The authors reported that lower acceptance, and greater levels of denial, planning, self-blame and self-distraction predicted more anxiety. In addition, other researchers reported that engaging in positive refocusing and goal reengagement led to greater positive affect, while less positive refocusing and more rumination and catastrophising predicted greater negative affect (Schroevers, Kraaij, & Garnefksi, 2008).

Groarke, Curtis and Kerin (2011) examined coping in 241 women with breast cancer at pre and post-surgery. Greater fighting spirit, lower anxious preoccupation, and avoidance predicted less depression, anxiety, and negative affect. Greater fighting spirit also predicted higher positive affect at pre-surgery. Post-surgery, fighting spirit predicted less depression and more positive affect, whilst anxious preoccupation predicted greater anxiety. Fatalistic coping also predicted greater negative affect. Between 4-11% of the variance was explained by coping at pre-
surgery, whilst 1-15% was explained at pre-surgery. By far the most significant predictor, however, was global stress, which accounted for between 32-59% of the variance in distress at pre-surgery, and 6-22% of the variance post-surgery.

**Coping during treatment**

Across the illness trajectory, many different challenges are faced, so coping may change in response to the demands of specific situations experienced. The coping strategies utilised during treatment may be very different to those used when initially diagnosed, or when treatment is completed. Coping has therefore also been assessed over time in women diagnosed with breast cancer, as well as specific coping during chemotherapy. Women recently diagnosed with breast cancer employed more active coping strategies to deal with the surgical aspects of the diagnosis, such as fighting spirit, but were less likely to use these strategies long-term (Boyes et al., 2009). Greater levels of anxious preoccupation and helplessness or hopelessness were utilised after treatment, and predicted higher levels of distress. In support of this, Wang and colleagues (2012) reported that women recently diagnosed with breast cancer reported higher fighting spirit which predicted less distress, whilst women 5 years post-surgery employed greater levels of fatalistic coping, contributing to more distress. Carver and colleagues (Carver et al., 1993) noted that at pre-surgery, women with breast cancer employed more active coping, planning, social support, positive reframing, religion, and self-distraction as effective ways to minimise distress, but these were used less frequently post-surgery.

Shapiro and colleagues (Shapiro et al., 1997) identified four types of coping in 56 women with stage II breast cancer receiving chemotherapy; confrontive, avoidant-confrontive, avoidant-resigned, and resigned. Analyses indicated that women who used confrontive coping reported better physical and psychological functioning than women who employed other coping strategies. This may be due to the fact that women who have more symptoms and side effects need to engage in more active coping to address the issues they experience. In support of this, Manne and colleagues (Manne et al., 1994) reported that confrontive coping and escape-avoidance were more common in 43 women who reported numerous symptoms of chemotherapy.
Bussell and Naus (2010) assessed coping with chemotherapy and distress in 59 women with breast cancer. Emotion-focused coping was used more frequently during chemotherapy, with the use of strategies such as self-blame predicting less posttraumatic growth and greater distress up to two years later. The use of problem-focused coping was related to a higher frequency of symptom reporting, indicating that women engage in more active coping strategies when confronted with challenges such as side effects.

Qualitative studies have also been conducted to try and develop detailed accounts of how women experience and cope with treatment. Drageset, Lindstrøm, and Underlid (2010) interviewed 21 women with breast cancer awaiting surgery and found that women engaged in a number of coping strategies. These included taking each obstacle step-by-step, redirecting attention to other events through distraction, maintaining activities, re-evaluating their priorities, and either expressing or suppressing emotions, as well as thinking positively. Although this study highlights the types of coping used, distress was not measured.

Waldrop, O’Connor, and Trabold (2011) interviewed 49 women 12 months after completing treatment. Analyses reveal that women experienced a number of physical and psychosocial stressors throughout treatment, which included treatment side effects, family concerns and fear of recurrence. To cope with these stressors, women engaged in activity-based coping, cognitive coping, positive appraisal, and spiritual coping. In particular, women engaged in scheduling activities or work to distract attention from treatment, as well as to aid in maintaining a routine. Similarly, women utilised cognitive strategies such as self-control over thoughts, as well as spiritual coping such as prayer.

Very few studies have examined coping with chemotherapy in general, but have instead focused on specific side effects of chemotherapy such as hair loss and fatigue. For example, Magnusson, Möller, Ekman, and Wallgren (1999) interviewed 15 cancer patients receiving chemotherapy about how they coped with fatigue. The methods utilised by participants to cope with fatigue included distraction, energy conservation, and engaging in physical activities such as walking. Planning and preparing for fatigue was a common form of coping strategy employed.

Hair loss is very distressing, and women engage in forms of coping to deal with this distress (Zannini et al., 2012). Frith, Harcourt, and Fussell (2007) examined anticipatory coping in chemotherapy in women with breast cancer. Women bought a
wig or cut their hair short to prepare for the inevitability of losing their hair once treatment commences. Additionally, the use of this form of coping functioned as a way to maintain control and decrease distress.

**Illness perceptions, coping, and breast cancer**

Despite the volume of studies that have assessed coping in women with breast cancer, only three studies have assessed both illness perceptions and coping in this disease group. In addition, these studies indicate that illness perceptions are much stronger predictors of distress than coping. For example, Rozema, Völlink, and Lechner (2008) examined illness perceptions, coping and mental and physical health in 119 women with breast cancer. When controlling for demographic factors, identity and consequences independently predicted 40% of the variance in physical health, with a strong illness identity and severe consequences predicting poorer physical health. Similarly, negative emotional representations and low treatment control independently explained 35% of the variance in poorer mental health. Coping did not predict any of the variance.

Millar, Purushotham, McLatchie, George, and Murray (2005) conducted a one-year prospective study with 371 women with breast cancer, and measured illness perceptions, coping and quality of life. Identity was predictive of distress at 3 months, while at 6 months, both identity and timeline were significant predictors. A strong illness identity and holding an acute timeline belief predicted greater levels of reported distress. At 12 months, timeline beliefs remained a significant predictor of distress. Although coping was measured, it did not predict distress or quality of life.

When compared to illness perceptions, coping may not predict much distress at diagnosis, but may be more important longer-term (Boyes et al, 2009; Wang et al., 2012). For example, McCorry and colleagues (McCorry et al., 2012) examined illness perceptions and coping in 72 women with breast cancer at diagnosis and six months post-diagnosis. After controlling for disease variables, holding more negative illness perceptions and engaging in less positive coping contributed to greater distress. Holding a more chronic timeline, more severe consequences, and a higher illness identity predicted almost 25% of the variance in anxiety at diagnosis, but only predicted 9.50% at 6 months. Similarly, illness perceptions predicted 20.50% of depression at diagnosis, but 11.30% at 6 months. Less positive-focused coping
predicted 10% of anxiety at diagnosis, but explained more variance (13.20%) at six months. Less positive-focused coping also predicted 13% of depression at diagnosis, but only 4.40% at six months.

**The Self-Regulatory Model and Cancer Risk Perceptions**

**Illness perceptions and experience of breast cancer**

Not all research that has examined illness perceptions in relation to breast cancer have been in women diagnosed with the disease. A further area of research includes differences in illness perceptions in women who do and do not have the disease. The Self-Regulatory model contends that illness perceptions are constructed from experience, so women with varying levels of experience with breast cancer will develop different perceptions of the disease (Rees, Fry, & Cull, 2001). In support of this, perceptions held by healthy women are different to women who are diagnosed with breast cancer. Buick and Petrie (2002) examined 78 healthy women and 78 women being treated for breast cancer. Healthy women reported lower control and more severe consequences than women who had the disease. In addition, healthy women reported greater chance-related, patient-related, genetic, and environmental causes than women with breast cancer did. Similarly, Katapodi and colleagues (Katapodi, Facione, Humphreys, & Dodd, 2005) found that the heuristics women employed to determine their perceived risk revolved around the belief that breast cancer can be avoided through lifestyle factors, contributing to the belief that women who develop breast cancer are considered to blame for developing the disease (Silverman et al., 2001).

Anagnostopoulos and Spanea (2005) examined illness perceptions in 102 women with cancer, with 147 women from the general population, with or without benign breast symptoms. Their findings suggest that women with breast cancer are more likely to hold stronger beliefs about environmental causes of breast cancer and more severe consequences, than healthy women and women with benign breast disease. In contrast, healthy women and those with benign disease reported higher perceptions of control or cure and greater chance attributions. Problems are evident in this study; however, as the data presented and the discussion surrounding the data are contradictory.
Perceptions of breast cancer can impact upon the behaviour of individuals towards cancer patients, as well as influencing adherence to treatment regimens or health care practices related to cancer prevention and detection (McCaul, Reid, Rathge, & Martinson, 1996). Healthy women who have negative perceptions of breast cancer may provide inappropriate support and place unrealistic expectations onto patients with cancer (Buick, 1997; Buick & Petrie, 2002). Holding very negative perceptions of the causes of cancer may lead to poor adherence rates for breast screening and breast self-examination behaviours (Buick & Petrie, 2002). In addition, perceiving high levels of personal control over detecting lumps was related to a higher frequency of breast self-examination (BSE; Mamon & Zapka, 1986; Payne, 1991). Screening adherence was also related to perceived personal control and causal attributions (Buick & Petrie, 2002; Russell, Champion, & Perkins, 2003). Concomitantly, women with greater perceived severity were less likely to attend for genetic testing for breast cancer (Katapodi, Northouse, Milliron, Liu, & Merajver, 2012).

Costanzo, Lutgendorf, and Roeder (2011) examined the perceived causes of breast cancer in 79 women, three weeks and three months post treatment for breast cancer. Women who believed that stress, diet and exercise were important causal factors for developing the disease, and rated breast cancer as having more serious consequences, were more likely to report improved diet and activity levels, and greater attempts to reduce stress. At the same time, women who believed that the causes of gynaecological cancer were controllable and still engaged in risk-increasing behaviours experienced greater distress (Costanzo, Lutgendorf, Bradley, Rose, & Anderson, 2005). The stronger the self-blame beliefs, the greater the distress reported. Christensen and colleagues (Christensen et al., 1999) reported that in 55 individuals with head and neck cancer, attributing the cause of the disease to past substance use, but having low perceived control over a future recurrence, predicted sustained smoking behaviour in patients diagnosed with the disease.

Although the SRM was constructed initially to explain a person’s response to illness, it is also useful to assess how illness perceptions can relate to perceptions of risk. The assessment of illness perceptions in women with and without breast cancer has led to an interest in how women who may be at risk of developing the disease in the future may perceive breast cancer. Research has therefore examined how the
Self-Regulatory model, and in particular illness perceptions, are related to perceptions of risk.

**Risk perceptions**

Risk perceptions are subjective, reasoned assessments of information relating to the likelihood of a threatening event taking place (Weinstein, 1999). There are two common forms of risk perceptions; absolute and comparative risk. In terms of breast cancer, absolute risk is defined as a subjective evaluation of personal risk of developing breast cancer. Comparative risk is the subjective evaluation of risk compared to others of similar age and characteristics of developing breast cancer (Lipkus, Klein, Skinner & Rimer, 2005).

One of the reasons why risk perceptions are considered important in breast cancer research is that they can predict levels of worry, as well as breast cancer screening in women. Numerous studies have assessed distress in women with a family history of breast cancer, as the heightened awareness of risk that comes from a family history may increase worry (Andersen, Smith, Meischke, Bowen, & Urban, 2003; Bennett et al., 2010; Hailey, Carter, & Burnett, 2000; Katapodi, Dodd, Lee, & Facione, 2009; Thewes, Meiser, Tucker, & Schneiden, 2003). McCaul, Branstetter, O’Donnell, Jacobsen, and Quinlan (1998) found that women with a family history reported more cancer worry than women without a family history. van Dooren and colleagues (van Dooren et al., 2005) reported higher levels of cancer-related distress in women who had at least one person in their family diagnosed with breast cancer. Furthermore, in 271 women applying for *BCRA1* and *BCRA2* testing, more cancer-related distress was reported 6 months after testing in women with a family history of breast cancer (Van Oostrom et al., 2007). It is important to note that general distress was not different across groups in any of these studies, suggesting that a family history of breast cancer only increases cancer-specific distress.

Studies that have specifically measured perceived risk of developing breast cancer show that risk perceptions are associated with worry and distress in both healthy women with no family history (Gurmakin Levy, Shea, Williams, Quistberg, & Armstrong, 2006; Lipkus, Klein, Skinner, & Rimer, 2005; Sjöberg, 1998), and in women with a family history of breast cancer (Hopwood, Shenton, Laloo, Evans, & Howell, 2001; Lerman et al., 1993; Lloyd et al., 1996; Mellon et al., 2008). Lipkus
and colleagues (Lipkus et al., 2000) assessed perceived risk in 581 healthy women, and found that women who report a high perceived risk of developing the disease also report more cancer-related worry. In addition, Lipkus Klein, Skinner, and Rimer (2005) reported that women with higher absolute and comparative risk perceptions were more likely to report higher levels of worry.

Risk perceptions can also influence the adoption of health-related behaviours, such as exercise and vaccination (Hampson, Andrews, Barckley, Lichtenstein, & Lee, 2006; van der Pligt, 1996), as well as breast cancer screening (Katapodi et al., 2004). Accurate knowledge of breast cancer risk as well as perceived efficacy of screening, are predictors of screening attendance (Mandelblatt et al., 1999; Royak-Schaler, Stanton, & Danoff-Burg, 1997). Lerman and colleagues (1991) assessed women’s distress and worry after mammography screening. Women who reported the highest levels of worry and highest risk perceptions had the strongest intentions to obtain mammography.

Although risk perceptions may be important in determining worry, some studies indicate that optimism may also be an important predictor. Whereas risk perceptions are the specific estimates of developing breast cancer in the future, optimism is a general positive outcome expectancy. This suggests that both may have an influence on distress. Optimism is related to less anxiety and distress (Henderson et al., 2008), and also to lower perceptions of risk in healthy women from the community (McGregor et al., 2004), but there is little research examining optimism and cancer-specific worry (Audrain et al., 1997; Henderson et al., 2008). Optimism is rarely included in studies measuring risk perceptions, despite their relationship to one another (Henderson et al., 2008). One of the few studies that measured optimism and risk perceptions found that women high in optimism underestimated their risk for developing breast cancer compared to their actual medical risk (McGregor et al., 2004). The mechanism by which optimism exerts its influence is little understood, but it is suggested that perceived risk of cancer may act as a mediator between optimism and cancer worry (McGregor et al., 2004). These constructs should be assessed for their interactions with one another, as they may both contribute to cancer-related worry.
Risk and illness perceptions

The Self-Regulatory model suggests that there is a link between risk and illness perceptions. Risk perceptions are similar to illness perceptions, in that personal beliefs of risk of illness can be developed from assessing health status, health habits, and family history of illness (Cameron, 2008). Linda Cameron developed the Assessment of Illness Risk Representations (AIRR; Cameron, 2008). The AIRR includes an imagery subscale, whereby participants are asked to list images that come to mind when they think about a particular illness. Cameron used this measure to elicit the imagery of skin cancer in 120 young adults (Cameron, 2008). She found that the descriptions given could be mapped onto the five dimensions of illness perceptions. This indicates that risk perceptions may be more associated to illness perceptions than previously assumed.

Risk judgements are constructed from likelihood estimates, and severity estimates. It has been suggested that these basic components of risk judgements are built upon illness perceptions (Cameron, 2003). Illness identity, cause, and timeline are considered to determine likelihood estimates. Identity provides a clear label of being ‘at risk’. Causal beliefs are related to factors that increase ones risk. Timeline beliefs are important for determining the perceived timing of when an illness will occur and the nature of the illness progression. In contrast, severity estimates relate more to perceived consequences and control. Consequence beliefs involve perceptions of disabilities and outcomes of illness. Control beliefs include perceptions of how an illness can be cured or controlled through medication, surgery, as well as appraisals of severity. Researchers agree that risk perceptions are distinct constructs, but may be influenced by all five illness cognitions (Marteau & Weinman, 2006).

The SRM has been used to explain perceptions of risk for developing breast cancer in 99 individuals undergoing genetic testing for $BCRA1/BCRA2$ mutations (Kelly et al., 2005). Kelly and colleagues (2005) found that participants who reported their risk as being higher held stronger hereditary and environmental causal attributions, lower personal control, and a more chronic timeline in terms of age of diagnosis and getting older. Those who considered their risk as lower than the population described their risk in terms of high treatment control (surgery and drugs as effective cures), and fewer causal attributions. Kaptein and colleagues (Kaptein et
al., 2007) examined risk and illness perceptions in 174 individuals with a genetic predisposition to venous thrombosis. Higher risk perceptions were correlated with higher identity, lower treatment control, and greater illness coherence and worry. Additionally, analyses were conducted to assess the mediating role of illness perceptions to the relationship between risk perceptions and worry. Although illness perceptions predicted risk perception and thrombosis worry, no mediation was found. Given this, an alternative may be that risk perceptions may mediate the relationship between illness perceptions and worry.

**Risk and illness perceptions and behaviour**

Although risk and illness perceptions have been indicated individually as predictors of worry and behaviour, they may be related. Risk and illness perceptions can be conceptualised as evaluations of a threat such as illness, and worry can be seen as the emotional response to that perceived threat (Cameron & Diefenbach, 2001). Shiloh, Drori, Orr-Urtreger, and Friedman (2009) examined cognitive representations to be ‘at-risk’. Participants who felt themselves ‘at risk’ were more likely to report genetics as a causal factor for cancer. In addition, causal attributions were associated with health anxiety and intrusive worrying thoughts. Worrying thoughts were predicted by risk perceptions and causal attributions, but only accounted for 14% of the overall variance. Health anxiety was also predicted by risk perceptions and causal attributions, and accounted for 23% of the variance. The authors surmise that being objectively at risk is represented by both risk perceptions and causal attributions, which are in turn related to worry and health anxiety. In this way, risk perceptions may mediate the relationship between illness perceptions and worry and behaviour, but the evidence is limited due to the paucity of research conducted.

As well as influencing emotional responses (distress) to an illness directly, the SRM can explain how risk perceptions influence behaviour (Kelly et al., 2005). According to the model, expectations of an event or illness exert their influence on behaviour (Cameron, 1997; Leventhal, Brisette, Leventhal, Cameron, & Leventhal, 2003). Risk information can interact with these beliefs (Cameron, 2003), and if this information is in competition with the pre-existing beliefs of the individual, action is less likely to be taken. For example, if a DNA test for bowel cancer risk does not fit
in with the identity of the condition being located in the bowel, the information may not be accepted. Identity is often seen to be hugely important; as it can influence the other four dimensions (Lau, Bernard, & Hartman, 1989). Causal beliefs are also important in determining action. According to the model, individuals engage in if/then rules, whereby if smoking causes lung cancer, then stopping smoking will reduce my risk of developing it in the future. In this way, if patients are told their genetic risk is high, but believe nothing can be done about genetics, they will be less motivated to engage in action. Similarly, when actions to reduce risk are not intuitively related with the genetic representation of the illness, individuals will be reluctant to accept the recommendations. This lack of symmetry between causes and coping may lead to higher rates of non-adherence and behaviour change.

Marteau and Weinman (2006) discussed the utility of the SRM in explaining the behaviour to DNA risk information. Genetic testing does not always translate into behaviour, and the SRM can explain this lack of motivation to act on threatening information. Health information activates both a cognitive response (danger control) and emotional response (fear control). If the emotional response is very strong, it may inhibit the ability of the individual to engage in any activity, as the efforts are focused on reducing fear, not the danger. Similarly, the engagement in behaviour based on genetic information is determined by the level at which action is considered an important goal, and if the information is in line with personal beliefs about cause. The model can also explain screening attendance for breast cancer. Women who believe they are at risk of developing breast cancer and also believe that screening will reduce their worry will engage in the behaviour, whereas women who believe that their worry will increase will be less likely to engage in screening. The inclusion of risk perceptions in the model provides a coherent explanation for both worry and screening behaviour.

The difficulty with assessing the relationship between risk and illness perceptions is that illness perceptions are often measured in patients who already have an illness, so the dimensions of the model in terms of risk perceptions may be different in healthy samples. Only one study has measured risk and illness perceptions in women in relation to breast cancer. Rees and colleagues (Rees, Fry, Cull, & Sutton, 2004) assessed 117 women at increased risk of developing breast cancer, and 100 healthy women with average risk of developing the disease. Healthy women with an average risk of developing breast cancer reported less cancer-
specific distress, more understanding of the illness, and perceived less severe consequences than women with a family history. In addition, healthy women were less likely to attribute breast cancer to hereditary, ageing, and hormonal factors, and were more likely to attribute a germ or virus, and poor medical care in the past as causes of breast cancer. In the increased risk group, risk perceptions predicted cancer worry, whilst higher identity scores predicted greater cancer worry in women with average risk.

There is some evidence that risk perceptions and illness perceptions are related (Cameron, 2003), but it may be a more useful approach to assess whether risk perceptions are a mediator of the relationship between illness perceptions and breast cancer worry. Rees and colleagues (2004) did not conduct mediation analyses, and Kaptein and colleagues (2007) assessed illness perceptions as a mediator, but did not confirm this relationship. Future research that examines the role of risk perceptions as a mediator is therefore warranted.

Methodological Considerations

A number of methodological issues arise in the research. In the three studies that have measured illness and coping in women with breast cancer, measures were completed at diagnosis (McCorry et al., 2012), before surgery (Millar et al., 2005) or within two years of diagnosis (Rozema et al., 2008); and all used different coping measures. This may not provide an accurate picture of the types of coping individuals employ to deal with the stressful events that necessitate specific coping across the illness trajectory, including during treatment such as chemotherapy. Generic instruments such as the COPE (Carver, Scheier, & Weintraub, 1989) and the Ways of Coping Questionnaire (Folkman & Lazarus, 1988) are reliable measures of general coping, but it has been argued that the use of these measures tend to reveal weaker relationships between illness perceptions and coping (Folkman & Lazarus, 1988). Examining specific coping strategies employed to deal with illness-related situations, such as the Mental Adjustment to Cancer Scale (Watson et al., 1988), is more appropriate within the context of the SRM.

Illness perceptions, coping, and distress are all measured by self-report, so there may be shared variance across constructs. Moreover, the majority of research is cross-sectional, using women recently diagnosed with breast cancer, or women who
are considered to be long-term survivors. Cross-sectional research is inadequate in determining the reciprocal relationship between coping and distress; baseline measures of distress cannot be controlled for, leading to an inability to establish whether illness perceptions are antecedents of distress. Additionally, very few of these studies also assessed coping, and none included coping appraisal. The exclusion of coping and coping appraisal limits the ability to examine the model as a whole. Much more rigorously designed research that includes prospective or longitudinal data is needed to confirm and therefore extend our knowledge of the predictive nature of the model.

Illness perceptions may be influenced by medical indices of disease, so it is vital that disease severity is assessed. Studies in women with breast cancer have used self-reported medical information, such as stage of disease and type of cancer (Lichtenstein Jørgensen et al., 2009; Rozema et al., 2008), whilst other studies have used medical records to obtain this information (McCorry et al., 2012; Millar et al., 2005). The inclusion of self-reported medical information is problematic, in that many cancer patients are unaware of their medical status (De Morgan et al., 2002; Rabin, et al., 2004). Disease information, confirmed by medical records, is required so that the influence of disease severity can be controlled.

Very few studies have found evidence that coping is a mediator between illness perceptions and distress (Gould, Brown, & Bramwell, 2010; Rutter & Rutter, 2002). Different statistical analyses have also been conducted. For example, the studies that have found a mediating role of coping have conducted path analyses (Gould et al., 2010; Rutter & Rutter, 2002), whilst those who have not found a relationship have conducted partial correlations (Dorrian et al., 2009; Heijmans, 1998). The use of more specified measures of coping for illness, and the use of consistent analyses may provide more evidence for the mediating role of coping.

There are models available that can determine a medical risk estimate for women, such as the Gail model (Gail et al., 1989). These medical risk estimates are often compared to risk perceptions to ascertain women’s accuracy of risk perceptions. There is much debate as to the most appropriate method of measurement (French & Marteau, 2008). Women can be classified as optimistic, accurate, or pessimistic; depending on the way risk is measured (French & Marteau, 2008; Woloshin, Schwartz, Black, & Welch, 1999). For example, numerical risk measures produce overestimations when compared to medical risk estimates,
whereas verbal measures produce an optimistic bias (Katapodi et al., 2004). As there is no gold standard with which to assess risk perceptions (Weinstein, 1999), the varied methods of assessment limits the comparisons that can be made across studies.

**Summary**

Overall, the SRM is a well-established model that explains how a person makes sense of their illness, and how their coping, behaviour and distress are influenced by illness perceptions. Illness perceptions are characterised by five dimensions that form a coherent pattern of illness. They have been measured using a number of reliable and validated questionnaires, most notably the IPQ and IPQ-R. The factor structure of illness perceptions has been confirmed across a wide number of studies and conditions, and predictable patterns have emerged across dimensions. Illness perceptions are well-defined, and their standardised measurement allows for the assessment of these perceptions in relation to other aspects of the model; namely coping and distress. The model asserts that illness perceptions guide responses to illness through coping; research does suggest that illness perceptions are related to certain types of coping strategies.

Illness perceptions are associated with psychological functioning and distress across a wide variety of illnesses, with more negative illness perceptions predicting poorer functioning and greater distress. Illness perceptions also predict distress via coping. Coping is considered to be a mediator of the relationship between illness perceptions and distress. Despite this, this relationship is not consistently confirmed in the literature. The model is considered to be cyclical, in that illness perceptions can guide coping and distress, whilst coping appraisal can determine distress by influencing illness perceptions and future coping. Some evidence for the influence of coping appraisal exists, but is limited by the paucity of research that has examined coping appraisal.

The Self-Regulatory model has been assessed for its ability to predict distress in women with breast cancer. A limited number of studies have measured illness perceptions in cancer patients, and found that they are predictive of distress. Coping, however, has received much more attention. The importance of coping in predicting distress in women with breast cancer, at diagnosis, throughout treatment, and across
the illness trajectory, is well documented. Problem-focused coping is associated with less distress, whilst emotion-focused coping predicts greater distress.

A small number of studies have looked at illness perceptions and coping in women with breast cancer (McCorry et al., 2012; Millar et al., 2005; Rozema et al., 2008). The results indicate that, contrary to the coping literature that suggests it is a strong predictor of distress, studies that have included both illness perceptions and coping assert that illness perceptions are better predictors of distress, but the mediating role of coping was not confirmed (McCorry et al., 2012; Rozema et al., 2008). Overall, the evidence for the influence of illness perceptions and coping on breast cancer distress is promising, but limited by the small number of studies that have been conducted. Furthermore, none of the studies have included coping appraisal, which stems in part from the lack of standardised measures of the construct.

Research examining how illness perceptions differ across women with varying levels of experience of breast cancer has led to an interest in how illness perceptions, family history of breast cancer, and perceptions of risk are related. There is no standardised measurement of risk perceptions, so research has often used family history as a measure of risk. Family history and risk perceptions can predict greater worry and are also associated with breast cancer screening attendance. There is also some evidence that risk and illness perceptions are related, and can influence worry and behaviour. Despite this, very little research has been conducted to examine these relationships, with only one study examining both risk and illness perceptions in relation to breast cancer. The SRM may be useful in integrating the role of risk and illness perceptions and in predicting behaviours such as screening (Cameron, 2003), and is a novel avenue of research.

There are a number of issues with the literature on the Self-Regulatory model. Most of the research focuses on one or two aspects of the model (e.g. illness perceptions or coping), rather than on the model as a whole. This leads to a fragmentation of the research, so that there are very few studies that can confirm the structure of the model as it was originally proposed. The Self-Regulatory Model is promising in explaining distress, but has rarely been used to explain levels of distress related to breast cancer. Research examining distress to a cancer diagnosis, and particularly in terms of distress involving treatment for cancer, may benefit from including the assessment of both illness perceptions and coping. Most of the research
conducted to date has been with patient groups, but expanding our knowledge of how illness and risk perceptions are related will be useful in the development of interventions to reduce distress in both ill and healthy populations.

**Overview of Current Research**

The current research assessed the role of the Self-Regulatory model in determining breast cancer-related distress in both healthy women and women with breast cancer. Additionally, these studies also explored the importance of coping and coping appraisal, in women with breast cancer.

**Study 1: Illness perceptions of breast cancer in healthy women**

Study 1 was divided into two sub-studies:

a) An examination of the role of risk perceptions and illness perceptions in predicting breast cancer worry and screening intentions in healthy women

b) A comparison of illness perceptions and distress (worry, anxiety, depression) in healthy women and women with breast cancer

In Study 1a), Nine hundred and forty eight women from the community completed measures of risk and illness perceptions, breast cancer worry, and screening intentions. In Study 1b), ninety nine healthy women divided into those with and without a family history of breast cancer, and sixty women with breast cancer, completed measures of illness perceptions and distress.

**Study 2: Illness perceptions and coping in women with breast cancer**

Study 2 assesses the role of illness perceptions and coping on distress in women with breast cancer at diagnosis and 12 months post-diagnosis.

One hundred and five women completed measures of illness perceptions, coping, and distress at diagnosis, and 57 of those women completed measures of distress 12 months post-diagnosis. The role of coping as a mediator of the relationship between illness perceptions and cancer-related distress was also explored.

**Study 3: Coping with chemotherapy for breast cancer – A qualitative study**

The majority of studies that have utilised the Self-Regulatory model have examined its ability to predict adjustment and distress to an illness, but have not always assessed how individuals cope with the specific threats that an illness creates.
Study 3 explores the coping strategies that women use when dealing with chemotherapy treatment. Twenty women diagnosed with breast cancer who required chemotherapy as part of their treatment, were interviewed about their coping strategies and their effectiveness during chemotherapy.
CHAPTER 3: STUDY 1

ILLNESS PERCEPTIONS OF BREAST CANCER IN HEALTHY WOMEN

STUDY 1a): An Examination of the Role of Risk Perceptions and Illness Perceptions in Predicting Breast Cancer Worry and Screening Intentions in Healthy Women

Rationale

Breast cancer worry is a specific concern, fear, anxiety, or worry about developing breast cancer in the future (Consedine, Magai, Krivoshekova, Ryzewicz, & Neugent, 2004). Breast cancer worry is important for its potential ability to influence adherence to breast cancer screening (Bennett et al., 2010; Diefenbach, Miller, & Daly, 1999; Hay, McCaul, & Magnan, 2006; Lerman et al., 1991; McCaul, Schroeder, & Reid, 1996; Payne, 1991), breast self-examination (Brain, Norman, Gray, & Mansel, 1999; van Dooren et al., 2003), as well as the decision to receive BCRA1/2 testing for breast cancer (Lerman et al., 1995). Both illness perceptions and risk perceptions have been implicated in predicting worry and screening behaviours, but only one study (Rees et al., 2004) has measured both, despite their potential importance in the Self-Regulatory model in determining response to an illness threat. The current study sought to address this by assessing the role of risk and illness perceptions in predicting breast cancer worry in healthy women from the community. Due to the lack of research on the relationship between risk and illness perceptions, and the assertion of the SRM (Cameron, 1997; 2003) that they are more than simply independent predictors of worry, the present study also examined the potential mediating influence of risk perceptions on the relationship between illness perceptions and breast cancer worry.
Other factors are also considered to be influential in determining breast cancer worry. For example, having a family history of breast cancer has previously predicted greater levels of breast cancer worry (Hailey et al., 2000; McCaul et al., 1998; van Oostrom et al., 2007). Family history was therefore measured for its ability to predict breast cancer worry in healthy women from the community. Similarly, higher levels of general anxiety are correlated with higher levels of specific breast cancer anxiety (Brain et al., 1999). Women who are prone to high levels of general distress are also more likely to experience high levels of cancer distress, but general distress is rarely controlled for. The present study included state and trait anxiety to control for the effect of general distress on breast cancer worry.

Optimism and risk perceptions are related constructs that have previously predicted breast cancer worry (Henderson et al., 2008). At the same time, risk perceptions have been implicated as a mediator to the relationship between optimism and breast cancer worry (McGregor et al., 2004). For this reason, optimism and risk perceptions were measured so that a clear understanding of how they contribute to breast cancer worry may be observed.

Illness perceptions may influence levels of breast cancer worry, but there is also some evidence that illness perceptions differ based on family history of breast cancer (Anagnostopoulos & Spanea, 2005; Buick & Petrie, 2002), so the present study compared healthy women with and without a family history of breast cancer for differences in these variables.

Risk perceptions are often measured for their ability to predict cancer-related worry (Lipkus et al., 2000; Sjöberg, 1998), but risk perceptions may also be related to general psychological outcomes such as anxiety, and depression (Bennett et al., 2010; Nordin et al., 2002). The current study explored differences in anxiety and depression, as well as cancer-related worry in women with high, average, or low perceptions of risk, so that a better understanding of their relationship to distress can be determined. Due to the varied methods of measurement, the present study measured perceptions of risk in numerical, verbal, ratio and comparative terms, as well as objective medical risk. In this way, comparisons can be made across methods to ascertain if they produce similar results.
Aims

The present study measures the impact of risk perceptions and illness perceptions for their influence on breast cancer worry in a sample of healthy women in the community. In addition, the study explores the impact of risk perceptions and illness perceptions on intentions to attend breast cancer screening and breast self-examination. Due to various other factors being implicated, the study also examines the impact of family history, general anxiety, and optimism on breast cancer worry.

Due to its potential relationship to breast cancer worry, the study examines whether absolute (numerical) risk perceptions mediate the relationship of illness perceptions and breast cancer worry. The study also investigates risk perceptions as a mediator to the relationship of optimism and breast cancer worry.

A further aim of this study was to examine the differences in risk perceptions and illness perceptions in healthy women with and without a family history of breast cancer. The current study also explores differences in general distress, such as anxiety, depression and cancer worry, in women who hold high, average, and low risk perceptions for breast cancer. The final aim was to explore the potential associations between the six types of measures of risk perceptions utilised in the study.

Specific Hypotheses

Predictors of Breast Cancer Worry

1. Higher levels of general anxiety (state and trait anxiety) predicts greater breast cancer worry
2. Higher risk perceptions and lower optimism predicts greater breast cancer worry
3. More negative illness perceptions (e.g. negative emotional representations, stronger illness identity) predicts greater breast cancer worry

Predictors of Screening Intentions and Breast Self-Examination

4. Having a family history of breast cancer predicts greater screening intentions and greater breast self-examination (BSE)
Chapter 3: Study 1

5. More experience with screening (doctor recommendation, number of mammograms received previously) and more positive screening attitudes will predict greater screening intentions and greater breast self-examination (BSE)

6. More confidence in performing breast self-examination predicts screening intentions and greater breast self-examination (BSE)

7. Greater breast cancer worry predicts higher screening intentions and greater breast self-examination (BSE)

8. Higher risk perceptions and lower optimism predicts higher screening intentions and greater breast self-examination (BSE)

9. More negative illness perceptions (e.g. negative emotional representations, stronger illness identity) predicts higher screening intentions and greater breast self-examination (BSE)

Mediation Analyses

10. Risk perceptions mediate the relationship between illness perceptions and breast cancer worry

11. Risk perceptions mediate the relationship between optimism and breast cancer worry

Impact of a Family History of Breast Cancer

12. Women with a family history of breast cancer report greater breast cancer worry than women without a family history of breast cancer

13. Women with a family history of breast cancer report differences in illness perceptions to women without a family history of breast cancer

14. Women with a family history of breast cancer report higher risk perceptions than women without a family history of breast cancer
Method

Participants

The sample comprised 948 women ($M = 29.93$ years, $SD = 11.74$) from the Republic of Ireland. Women were included if they were 18 years of age or over, without a previous diagnosis of breast cancer, and able to read and write English. A summary of demographic information of participants can be seen in Table 1. The majority of respondents were Anglo-Saxon in their cultural background (98.40%), with a minority from Asian, African and mixed ethnicity (1.60%). Most women were single (55.00%), married (24.50%), or cohabiting (17.10%), with 3.40% of women divorced, separated or widowed.

Procedure

Ethical approval was obtained from the National University of Ireland, Galway Research Ethics Committee. Information about the study, along with contact details of the researcher, was sent to various organizations such as health centres and workplaces in Ireland via email, websites, and print information. Those who contacted the researcher chose to receive either an email with a link to the survey online or a questionnaire packet via post to complete anonymously. The online version consisted of the same questions available on a web-based survey tool (it could be completed by any computer with internet availability). An incentive of entry into a draw for a nominal prize (a €50 gift voucher) was offered to those who completed and returned the questionnaire. First and second year NUI, Galway psychology students received course credit (as part of a credit-based programme available only to first and second years) for participation.

Materials and Measures

Basic demographic information was collected, including age, and marital and employment status. Knowledge of cancer was assessed by asking participants to indicate whether they had ever studied a cancer-related topic in college, or had ever worked for a charity, organization or health services in a cancer-related field. In
addition, participants were asked to report the symptoms of breast cancer, and to indicate whether any friends or colleagues had been diagnosed with breast cancer.

**Risk factor information**

Family history of breast cancer was measured using a series of questions that asked participants to indicate whether any immediate female relatives (mother, sister, grandmother) had ever been diagnosed with breast cancer. Participants were also asked to report whether any other female relatives (aunt, niece, cousin), had ever been diagnosed with breast cancer.

Medical risk for developing breast cancer was measured using the Breast Cancer Risk Assessment Tool, or Gail Model (Gail et al., 1989). It is a method used to estimate the chance of a woman developing breast cancer over a specific time interval (five year risk, lifetime risk), based on the presence of medical risk factors for breast cancer. It is a commonly used tool to aid in risk counselling in Caucasian populations, but is less effective in Hispanic or African American populations (Decarli et al., 2006; Gail et al., 2007). Moreover the tool is less effective in predicting risk in younger women, and overestimates risk in women classified in the highest quintile (Costantino et al., 1999). In the present study its use was limited to assessing medical risk of developing cancer in women who were 35 years or older. It consists of questions measuring participants’ age, ethnicity, age at first menses, and if applicable, age at first live birth, and family history. The final questions asked participants to indicate how many breast biopsies they had experienced (if any), and to indicate if any of the biopsies were positive for atypical hyperplasia (a strong medical risk factor for future development of the disease).
Table 1.

Summary Frequencies of Demographic Variables \((N = 948)\)

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian (Anglo-Saxon)</td>
<td>934</td>
<td>98.40</td>
</tr>
<tr>
<td>Other (African/Asian/mixed)</td>
<td>14</td>
<td>1.60</td>
</tr>
<tr>
<td>Marital status</td>
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<td></td>
</tr>
<tr>
<td>Single</td>
<td>522</td>
<td>55.00</td>
</tr>
<tr>
<td>Cohabiting</td>
<td>161</td>
<td>17.10</td>
</tr>
<tr>
<td>Married</td>
<td>232</td>
<td>24.50</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>24</td>
<td>2.50</td>
</tr>
<tr>
<td>Widowed</td>
<td>9</td>
<td>0.90</td>
</tr>
<tr>
<td>Employment Status</td>
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<td></td>
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<tr>
<td>Full-time employment</td>
<td>391</td>
<td>41.30</td>
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<tr>
<td>Part-time employment</td>
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<td>15.50</td>
</tr>
<tr>
<td>Working in the home</td>
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<td>2.80</td>
</tr>
<tr>
<td>Semi-retired/Retired</td>
<td>13</td>
<td>1.40</td>
</tr>
<tr>
<td>Not working</td>
<td>24</td>
<td>2.50</td>
</tr>
<tr>
<td>Student</td>
<td>346</td>
<td>36.50</td>
</tr>
</tbody>
</table>
Breast screening behaviour

Due to the lack of standardised measures, the authors developed a set of questions to assess mammography screening intentions and attitudes to mammography; similar to those used previously (Diefenbach et al., 1999; Hay et al., 2006; McCaul, Schroeder, & Reid, 1996). Participants were asked to indicate how often they perform breast self-examination (BSE), ranging from 0 (never) to 5 (more than once a month). Confidence in ability to perform breast self-examinations was assessed by asking women to rate their confidence from 1 (not at all confident) to 5 (very confident).

Mammography screening was assessed by first asking participants if a doctor had ever recommended a mammogram, and if participants had ever had a mammogram. Reasons included being too young for a mammogram, personal assessment of breast cancer risks, and perceived benefits or harms. Those who reported having a mammogram were asked to indicate how many they had, and when they attended their last mammogram (less than a year, 1-2 years, more than 2 years ago, not sure).

Attitudes to mammography screening were assessed by asking women to rate how much they agreed to a number of statements regarding breast cancer screening. Women were asked to rate the statements on a five point Likert scale from 1 (strongly disagree) to 5 (strongly agree). Statements included breast cancer screening is: easy, useful, uncomfortable, accurate in detecting breast cancer, worrying, important, inconvenient, painful, reassuring, and embarrassing. Items were reverse-scored and summed to give a total screening attitudes score. Women were also asked to rate their intention of attending the free national breast cancer screening programme in Ireland (BreastCheck) in the future, from 1 (definitely not) to 5 (definitely yes).

Risk perceptions

Perceptions of absolute breast cancer risk were assessed using six questions adapted from Gurmankin Levy and colleagues (Gurmankin Levy et al., 2006). Participants were asked to rate the likelihood of developing breast cancer in one’s lifetime, and also in the next five years, from 0 (you definitely will not be diagnosed
with breast cancer) to 100 (you definitely will be diagnosed with breast cancer). Perceptions were also measured verbally (how would you rate the chance of developing breast cancer; very low, moderately low, neither high nor low, moderately high, very high), and in ratios (what is the likelihood of developing breast cancer someday; 1 in 100, 1 in 50, 1 in 25, 1 in 10, 1 in 5, 1 in 2, no chance). Participants were also asked to rate how vulnerable they felt to getting breast cancer at some point in their lifetime from 1 (not at all) to 7 (extremely). In addition, participants were asked to rate how severe breast cancer would be if they developed it at some point in their life, from 1 (not at all) to 7 (extremely).

Comparative risk perceptions were assessed by asking women to rate the likelihood of the average woman developing breast cancer from 0 (you definitely will not be diagnosed with breast cancer) to 100 (you definitely will be diagnosed with breast cancer), and also verbally (very low, moderately low, neither high nor low, moderately high, very high). Comparative risk perceptions were also measured using a single item asking women to rate their chance of developing breast cancer in comparison to that of the average woman (much lower, slightly lower, about the same, slightly higher, much higher). Finally, the average woman’s likelihood of having breast cancer someday was assessed in ratios (1 in 100, 1 in 50, 1 in 25, 1 in 10, 1 in 5, 1 in 2, no chance).

**Optimism**

Dispositional optimism was measured using the Life Orientation Test (LOT; Scheier, Carver & Bridges, 1994). This scale consists of 8 items and 4 filler items that ask participants to rate how much they agree or disagree with statements related to dispositional optimism on a five point scale ranging from 0 (I disagree a lot) to 4 (I agree a lot). Four of the items are reverse scored, and all items are summed to give a total score. Higher scores indicate a higher level of dispositional optimism. The measure has shown good internal consistency (Cronbach’s $\alpha = .76$) and test-retest reliability (Johnston, Wright & Weinman, 1988). In more recent research in women at risk of breast cancer, internal reliability was reported as Cronbach’s $\alpha = .73$ (McGregor et al., 2004).
Illness perceptions

Illness perceptions were measured using the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002), modified for a healthy population. Respondents are asked to rate their agreement with statements about breast cancer. All the items are rated on five point Likert scales ranging from 1 (strongly disagree) to 5 (strongly agree), except for those in the identity dimension. The identity subscale was modified for a healthy population, and asks respondents to indicate from a list of symptoms, whether they believe they are symptoms of breast cancer. The questionnaire yields a total of eight subscales: timeline (acute/chronic), cyclical timeline, consequences, identity, personal control, treatment control, emotional representations, and illness coherence. The causal subscale is scored by conducting factor analysis on the items to create causal factors (Moss-Morris et al., 2002). Internal reliabilities for the subscales (Cronbach’s α) range from .75 to .89 (Hagger & Orbell, 2003; 2005), with acceptable reliability reported in previous cancer patient samples (Dempster & McCorry, 2012).

Distress

Breast cancer worry was assessed by four questions adapted from previous research (Cameron & Diefenbach, 2001; Lipkus et al., 2005). Lipkus and colleagues (2005) previously asked how fearful, worried and anxious participants were of getting breast cancer in their lifetime, and reported excellent internal reliabilities at baseline (α = .86), and at follow-up (α = .89). The definition of worry also includes concern (Consedine et al., 2004), so a fourth item, ‘how concerned are you about getting breast cancer’, was included in the current study. All 4 items were scored from 1 (not at all) to 5 (extremely). Higher scores indicate higher levels of breast cancer worry. Internal reliability for the current sample was deemed appropriate (α = .94), with divergent validity evidenced by its modest association with measures of general anxiety (r = .26, p < .001) and depression (r = .15, p < .001), as measured by the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was used to measure general anxiety and depression levels. The HADS is a 14 item scale (7 items for anxiety, 7 for depression) that asks individuals to indicate their level of agreement with statements on a four point scale from 0 (e.g. most of
the time) to 3 (e.g. not at all). Higher scores indicate greater levels of anxiety or depression. A score of 11 is considered the cut-off for detecting mood disorders, and displays a sensitivity score of 70% and a specificity score of 88% when compared to clinical interviews and other psychological measures (Morasso et al., 2001). Internal consistency has been reported to be .93 for anxiety and .90 for depression (Moorey et al., 1991).

The Spielberger State-Trait Anxiety Scale (STAI; Spielberger, Gorsuch, & Lushene, 1970) was used to measure both state and trait anxiety in the current sample. For the trait subscale, participants were asked to indicate their agreement to 20 statements about how they generally feel on a 4 point scale from 1 (not at all) to 4 (almost always). The state subscale also consists of 20 items, which participants must rate based on how they feel at this moment, on a 4 point scale from 1 (not at all) to 4 (very much so). Items are reverse scored and summed to give a total trait anxiety and total state anxiety score. Across a wide range of studies, average Cronbach’s α has been reported as .91 for state anxiety and .89 for trait anxiety (Barnes, Harp, & Jung, 2002; Bieling, Antony, & Swinson, 1998).
Chapter 3: Study 1

Results

Data Analysis

Pearson Product Moment correlations were conducted to examine the relationships between the factors hypothesised to contribute to breast cancer worry. Hierarchical multiple regressions were conducted to examine the predictors of breast cancer worry (Hypotheses 1-3), intention to attend mammography screening and breast self-examination (Hypotheses 4-9). Mediation analyses were conducted to examine the mediating role of risk perceptions to the relationship between illness perceptions and breast cancer worry (Hypothesis 10), in line with Baron and Kenny’s method for testing mediation (Baron & Kenny, 1986). Mediation analyses were also conducted to assess the role of risk perceptions as a mediator between optimism and breast cancer worry (Hypothesis 11). An independent Samples t test was conducted to examine whether women with a family history report greater breast cancer worry than women without a family history (Hypothesis 12). One-way between-subjects ANCOVAs were conducted to determine differences in illness perceptions according to family history of breast cancer, controlling for breast cancer worry (Hypotheses 13-14). One-way between-subjects ANOVAs were conducted to explore the differences in distress levels, in women classified as optimistic, accurate, or pessimistic based on risk perceptions. Finally, a Chi Squared test was conducted to examine associations between the six types of risk perceptions.

A sample of at least 300 is required to conduct factor analyses (Tabachnik & Fidell, 2007). In addition, a sample of 151 women aged 35 years or more were required so that Chi Squared analyses with a medium degree of association, examining differences across medical risk and risk perceptions, could achieve 80% power (Cohen, 1992). A sample of 156 women was also required to achieve 80% power for the ANOVAs with three groups and an estimated medium effect size. Analyses were conducted to assess the achieved power based on the obtained sample size. Using G*Power software (Faul, Erdfelder, Lang, & Buchner, 2007), 99.6% power was achieved for the regression analyses, whilst the Chi Squared test achieved 97.8%. The ANOVAs and ANCOVAs achieved 100% power.
Data Preparation

All variables were assessed for normal distribution. As can be seen in Table 2, almost all the variables fell within an acceptable range of skew values (< .80). The exceptions to this were age (skew value = 1.00, \( SE = 0.09 \)), depression (skew value = 1.22, \( SE = 0.08 \)), and five year risk (skew value = 1.43, \( SE = 0.09 \)). These variables were positively skewed. Logarithmic transformations were conducted on these variables, and reduced the skew values (0.51, -0.02, and -0.59 respectively), so were used in subsequent analyses. Means and standard deviations reported are from the original data.

Missing value analyses were performed on the data. During data collection, a technical error occurred in the online survey, which resulted in a failure to collect measures of the LOT and HADS for approximately 100 participants. These participants were excluded when analyses included the measures, but were otherwise included in other analyses. Analysis of the remaining missing values indicated that the percentage of missing data was below 10% for each subscale. Tabachnick and Fidell (2007) advocate the use of a series mean in cases such as these, so missing data were replaced with the series mean in these instances.

Reliability analyses were conducted for each of the measures (as can be seen in Table 2). The majority of subscales received Cronbach’s alpha levels of .70 or more, with the exception of the consequences (Cronbach’s \( \alpha = .62 \)), treatment control (Cronbach’s \( \alpha = .67 \)), cyclical timeline (Cronbach’s \( \alpha = .67 \)), and screening attitudes (Cronbach’s \( \alpha = .66 \)).

Knowledge of Breast Cancer

As can be seen in Table 3, most women in the sample identified a breast lump as a symptom of breast cancer (90.40%). Almost a third identified breast pain tenderness or discomfort as a symptom (30.80%), whilst changes in the breast shape or colour was reported by 20.40% of women. Fifteen women (1.60%) reported symptoms of breast cancer treatment as symptoms of breast cancer. Very few women had experience with cancer through work (0.50%) or through taking part in a course (3.50%). Almost 40% of the sample had known a friend or colleague who
developed breast cancer, whilst more than half reported no family history of breast cancer (55.30%). Forty three women (4.50%) did not know their family history status, so were excluded from analyses that included this variable.
Table 2.

*Psychometric Properties of the Demographic and Psychological Variables*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>M</th>
<th>SD</th>
<th>α</th>
<th>Potential</th>
<th>Actual</th>
<th>Skew</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>948</td>
<td>29.93</td>
<td>11.74</td>
<td>-</td>
<td>18-70</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>Mean cancer worry</td>
<td>961</td>
<td>2.83</td>
<td>1.00</td>
<td>.94</td>
<td>1-5</td>
<td>1-5</td>
<td>-0.03</td>
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<td><strong>HADS</strong></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>836</td>
<td>7.51</td>
<td>3.98</td>
<td>.82</td>
<td>0-21</td>
<td>0-21</td>
<td>0.51</td>
</tr>
<tr>
<td>Depression</td>
<td>835</td>
<td>3.42</td>
<td>3.06</td>
<td>.77</td>
<td>0-21</td>
<td>0-18</td>
<td>1.22</td>
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<tr>
<td><strong>STAI</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>State Anxiety</td>
<td>927</td>
<td>38.16</td>
<td>10.82</td>
<td>.93</td>
<td>20-80</td>
<td>20-80</td>
<td>0.49</td>
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<td>Trait Anxiety</td>
<td>920</td>
<td>41.23</td>
<td>10.46</td>
<td>.93</td>
<td>20-80</td>
<td>20-78</td>
<td>0.36</td>
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<tr>
<td><strong>IPQ-R</strong></td>
<td></td>
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<td>Identity</td>
<td>825</td>
<td>10.37</td>
<td>3.43</td>
<td>.81</td>
<td>0-17</td>
<td>0-17</td>
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<tr>
<td>Personal Control</td>
<td>870</td>
<td>20.99</td>
<td>3.66</td>
<td>.72</td>
<td>6-30</td>
<td>8-30</td>
<td>-0.02</td>
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<tr>
<td>Treatment Control</td>
<td>871</td>
<td>18.80</td>
<td>2.61</td>
<td>.67</td>
<td>5-25</td>
<td>11-25</td>
<td>-0.03</td>
</tr>
<tr>
<td>Consequences</td>
<td>871</td>
<td>23.23</td>
<td>3.13</td>
<td>.62</td>
<td>6-30</td>
<td>12-30</td>
<td>-0.21</td>
</tr>
<tr>
<td>Chronic Timeline</td>
<td>869</td>
<td>18.82</td>
<td>3.25</td>
<td>.70</td>
<td>6-30</td>
<td>8-29</td>
<td>0.35</td>
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<tr>
<td>Cyclical Timeline</td>
<td>867</td>
<td>12.35</td>
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<td>.67</td>
<td>4-20</td>
<td>4-20</td>
<td>-0.33</td>
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<tr>
<td>Illness Coherence</td>
<td>869</td>
<td>16.03</td>
<td>4.30</td>
<td>.90</td>
<td>5-25</td>
<td>5-25</td>
<td>-0.18</td>
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<tr>
<td>Emotional Representations</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Causal Subscales</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Psychological</td>
<td>845</td>
<td>16.93</td>
<td>4.85</td>
<td>.87</td>
<td>6-30</td>
<td>6-30</td>
<td>-0.16</td>
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<tr>
<td>Behavioural</td>
<td>843</td>
<td>13.61</td>
<td>2.90</td>
<td>.69</td>
<td>4-20</td>
<td>4-20</td>
<td>-0.63</td>
</tr>
<tr>
<td>External</td>
<td>845</td>
<td>7.46</td>
<td>2.06</td>
<td>.47</td>
<td>3-15</td>
<td>3-15</td>
<td>-0.05</td>
</tr>
<tr>
<td>Medical</td>
<td>840</td>
<td>19.96</td>
<td>2.75</td>
<td>.48</td>
<td>5-25</td>
<td>5-25</td>
<td>-0.44</td>
</tr>
<tr>
<td>Risk Perceptions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical risk</td>
<td>247</td>
<td>12.43</td>
<td>5.06</td>
<td>-</td>
<td>0-100</td>
<td>5-56.20</td>
<td>-</td>
</tr>
<tr>
<td>Lifetime risk %</td>
<td>920</td>
<td>37.20</td>
<td>21.43</td>
<td>-</td>
<td>0-100</td>
<td>0-100</td>
<td>0.25</td>
</tr>
<tr>
<td>Five-year risk %</td>
<td>916</td>
<td>18.89</td>
<td>19.72</td>
<td>-</td>
<td>0-100</td>
<td>0-100</td>
<td>1.43</td>
</tr>
<tr>
<td>Verbal estimate</td>
<td>918</td>
<td>2.61</td>
<td>0.93</td>
<td>-</td>
<td>1-5</td>
<td>1-5</td>
<td>-0.04</td>
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<tr>
<td>Ratio risk</td>
<td>919</td>
<td>4.43</td>
<td>1.80</td>
<td>-</td>
<td>1-7</td>
<td>1-7</td>
<td>-0.27</td>
</tr>
<tr>
<td>Vulnerability</td>
<td>922</td>
<td>3.75</td>
<td>1.31</td>
<td>-</td>
<td>1-7</td>
<td>1-7</td>
<td>-0.01</td>
</tr>
<tr>
<td>Severity</td>
<td>920</td>
<td>5.00</td>
<td>1.42</td>
<td>-</td>
<td>1-7</td>
<td>1-7</td>
<td>-0.45</td>
</tr>
<tr>
<td>Ave. lifetime risk %</td>
<td>898</td>
<td>38.40</td>
<td>18.64</td>
<td>-</td>
<td>0-100</td>
<td>0-99</td>
<td>0.11</td>
</tr>
<tr>
<td>Ave. verbal risk</td>
<td>912</td>
<td>3.08</td>
<td>0.76</td>
<td>-</td>
<td>1-5</td>
<td>1-5</td>
<td>0.15</td>
</tr>
<tr>
<td>Average ratio risk</td>
<td>912</td>
<td>4.36</td>
<td>1.47</td>
<td>-</td>
<td>1-7</td>
<td>1-7</td>
<td>-0.16</td>
</tr>
<tr>
<td>Comparative risk</td>
<td>914</td>
<td>2.83</td>
<td>0.80</td>
<td>-</td>
<td>1-5</td>
<td>1-5</td>
<td>-0.24</td>
</tr>
<tr>
<td>Optimism (LOT)</td>
<td>831</td>
<td>20.20</td>
<td>6.88</td>
<td>.88</td>
<td>0-32</td>
<td>0-30</td>
<td>-0.31</td>
</tr>
<tr>
<td>Screening Attitudes</td>
<td>905</td>
<td>37.16</td>
<td>4.46</td>
<td>.66</td>
<td>10-50</td>
<td>24-50</td>
<td>0.10</td>
</tr>
</tbody>
</table>

*Note.* HADS = Hospital Anxiety and Depression Scale; STAI = State Trait Anxiety Inventory; IPQ-R = Revised Illness Perception Questionnaire; LOT = Life Orientation Test
### Table 3.
**Summary Frequencies for Knowledge of Breast Cancer (N = 948)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family history of breast cancer</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No family history</td>
<td>524</td>
<td>55.30</td>
</tr>
<tr>
<td>One immediate relative</td>
<td>97</td>
<td>10.20</td>
</tr>
<tr>
<td>Other relative</td>
<td>207</td>
<td>21.90</td>
</tr>
<tr>
<td>More than one relative</td>
<td>77</td>
<td>8.10</td>
</tr>
<tr>
<td>Unknown</td>
<td>43</td>
<td>4.50</td>
</tr>
<tr>
<td><strong>Symptoms reported</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lump or cyst</td>
<td>856</td>
<td>90.40</td>
</tr>
<tr>
<td>Breast changes (shape, colour)</td>
<td>193</td>
<td>20.40</td>
</tr>
<tr>
<td>Breast pain, tenderness or discomfort</td>
<td>292</td>
<td>30.80</td>
</tr>
<tr>
<td>Nipple changes (colour, shape)</td>
<td>100</td>
<td>10.50</td>
</tr>
<tr>
<td>Nipple discharge</td>
<td>139</td>
<td>14.70</td>
</tr>
<tr>
<td>Skin changes (rash)</td>
<td>71</td>
<td>7.50</td>
</tr>
<tr>
<td>Swelling</td>
<td>69</td>
<td>7.30</td>
</tr>
<tr>
<td>Arm swelling/lump</td>
<td>125</td>
<td>13.20</td>
</tr>
<tr>
<td>No symptoms/ unknown</td>
<td>17</td>
<td>1.70</td>
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<tr>
<td>General feelings of illness (e.g. fatigue)</td>
<td>137</td>
<td>14.50</td>
</tr>
<tr>
<td>Treatment symptoms</td>
<td>15</td>
<td>1.60</td>
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<tr>
<td><strong>Experience of cancer through work</strong></td>
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<td></td>
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<tr>
<td>No experience</td>
<td>858</td>
<td>90.50</td>
</tr>
<tr>
<td>Cancer charity / organisation</td>
<td>5</td>
<td>0.50</td>
</tr>
<tr>
<td>Worked in health services</td>
<td>22</td>
<td>2.30</td>
</tr>
<tr>
<td>Cancer course</td>
<td>32</td>
<td>3.50</td>
</tr>
<tr>
<td>Multiple</td>
<td>22</td>
<td>2.30</td>
</tr>
<tr>
<td>Other experiences</td>
<td>9</td>
<td>0.90</td>
</tr>
<tr>
<td><strong>Friends or colleagues diagnosed</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>378</td>
<td>39.70</td>
</tr>
<tr>
<td>No</td>
<td>570</td>
<td>60.30</td>
</tr>
</tbody>
</table>

*Note. Multiple symptoms were endorsed by participants.*
Factor Structure of the Causal IPQ-R Subscale

It is recommended that factor analysis is conducted within each sample of the causal subscale of the IPQ-R to allow for the most suitable groupings (Dempster et al., 2011; Moss-Morris et al., 2002). An exploratory factor analysis was therefore conducted to determine the factor structure of the causal subscale of the IPQ-R. An initial Principal Components Analysis with all 19 items from the subscale was conducted. The analysis produced 5 components with eigenvalues greater than 1, which was confirmed by the scree plot. Upon examination of the components, the fifth component was un-interpretable, so the PCA was re-run with a forced four-component solution. One item, *a person’s behaviour*, loaded similarly across three of the components, so was removed from the subsequent analyses. The final analysis with varimax rotation resulted in the first component denoting psychological causes. The second component was labelled behavioural and environmental causes, and included causes such as smoking, drinking alcohol, and pollution. The third component denoted external factors such as poor medical care in the past, accident or injury, and germ or virus. The fourth component was related to medical risk factors, and displayed the causes of breast cancer that have the most scientific and medical evidence; namely hormones, ageing, and hereditary (See Table 4). The Kaiser-Meyer-Olin (KMO) value was .85, greater than the recommended value of .60 or more (Hutcheson & Sofroniou, 1999; Kaiser, 1974). Bartlett’s Test of Sphericity was significant ($\chi^2 = 4418.67, df = 153, p < .001$), indicating factorability of the correlation matrix. The four-component solution explained 52.14% of the variance. Low reliability scores were reported for external ($\alpha = .47$) and medical causes ($\alpha = .48$). Previous research has reported that Cronbach’s alpha is not a reliable measurement of consistency when used for subscales with very few items (Cortina, 1993), so despite the low alpha levels, the subscales were retained for the analyses.
Table 4.  
*Factor Loadings for Principal Components Analysis with Varimax Rotation for the Causal Subscale of the IPQ-R*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Psychological</th>
<th>Behavioural</th>
<th>External</th>
<th>Medical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional state</td>
<td>.84</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family problems</td>
<td>.83</td>
<td></td>
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*Note. Only factor loadings > .30 are shown; the highest loadings are in bold.*
Prevalence of Distress

More than half of the sample reported low levels (0-7) of anxiety (54.20%), whilst most of the sample reported very low levels of depression (88.60%). Using the cut-off scores of 11 to determine clinical levels of distress in the HADS (Morasso et al., 2001), 173 women (21.30%) reported probable clinical levels of anxiety, whilst only 22 women (2.70%) reported probable clinical levels of depression. Only 112 women (11.80%) reported high levels of breast cancer worry, defined as a score of 4 or more.

Intercorrelations between Risk Perceptions, Illness Perceptions, and Breast Cancer Worry

A series of Pearson Product Moment correlations were conducted to examine the relationships between psychological variables, risk and illness perceptions (See Table 5). Breast cancer worry was negatively correlated with optimism ($r = -.25, p < .001$), personal control ($r = -.11, p < .001$), and treatment control ($r = -.12, p < .001$). It was positively correlated with all other variables, with the exceptions of illness coherence ($r = -.02, p = .652$), psychological ($r = .05, p = .180$), and medical causes ($r = .03, p = .423$), which were not significant. Breast cancer worry was positively correlated with all risk perception measures, except for ratio risk ($r = .01, p = .695$), and the Gail medical risk estimate ($r = .12, p = .057$). All correlations were small to moderate ($r = .08 - .55$).

A series of Pearson Product Moment correlations were conducted to examine the relationships between the risk and illness perception measures (See Table 6). Regarding absolute risk perceptions, numerical and verbal risk were positively correlated with chronic and cyclical timeline, consequences, emotional representations, and negatively correlated with personal and treatment control. Similarly, five year numerical risk was correlated with chronic timeline, emotional representations, external causes, and negatively correlated with personal control. Ratio risk was correlated with external causes only ($r = -.07, p = .032$). Comparative risk estimates were positively correlated with chronic timeline ($r = .16, p < .001$), consequences ($r = .09, p = .011$), and emotional representations ($r = .21, p < .001$). The medical risk estimate was negatively correlated with chronic timeline only ($r = -$.
.17, \( p = .012 \)). Optimism was also negatively correlated with all risk perceptions, except for ratio risk \( (r = -.03, \ p = .360) \), and Gail medical risk estimate \( (r = -.01, \ p = .390) \), which were not significant.

All of the risk perception measures were positively correlated with one another, except for ratio measurement. The ratio risk measure was negatively correlated with average woman's numerical risk \( (r = -.07, \ p = .033) \) vulnerability ratings \( (r = -.08, \ p = .017) \), and verbal risk \( (r = .11, \ p = .001) \).
Table 5.
Summary of Correlations between Age, Family History, Distress, Risk Perceptions, and Illness Perceptions

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*p < .05, **p < .01, ***p < .001
### Chapter 3: Study 1

**Table 6. Summary of Intercorrelations between Risk Perceptions and Illness Perceptions**

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*p < .05, **p < .01, ***p < .001
Factors Predicting Breast Cancer Worry

To test the hypothesis that risk and illness perceptions predict breast cancer worry (Hypotheses 1-3), a hierarchical multiple regression was conducted. The variables were entered in blocks, so that each block of variables could be examined for their additional contribution to the variance. A series of Pearson Product Moment correlations were conducted to assess which demographic variables should be controlled. Only age ($r = -.13, p < .001$) and family history ($r = .16, p < .001$) were correlated with breast cancer worry, so were entered in the first step. State and trait anxiety were entered into the second step to control for general anxiety. Risk perceptions are considered important in the development of perceptions of illness (Cameron, 1997), and optimism is considered a general outcome expectancy related to risk perceptions. For these reasons, risk perceptions and optimism were entered in the third step. Illness perceptions were included in the final step.

The issue of multicollinearity was assessed by first examining bivariate correlations between the predictor variables. Correlations ranged from $r = .08$ to $r = .52$, whilst the VIF scores ranged from 1.08 to 3.23 (tolerance scores ranged from 0.31 to 0.93), indicating that multicollinearity was not present in the sample. Emotional representations may hold some shared variance with breast cancer worry, but the correlation between variables was moderate ($r = .55, p < .001$), and has been used in the past to predict variables such as depression (Giannousi, et al., 2010), so was deemed appropriate to include it in the current analyses.

As can be seen from Table 7, Hypotheses 1 to 3 were confirmed. The overall model was significant, accounting for 42% of the variance in breast cancer worry ($F_{(22,702)} = 25.14, p < .001, R^2 = .44, Adj R^2 = .42$). Age and family history explained 3% of the variance in breast cancer worry, but the beta weights were not significant. State anxiety accounted for 8% of the variance, with higher levels of state anxiety ($\beta = .11, p = .011$) predicting higher worry levels. Risk perceptions accounted for 17% of the variance, with women holding higher numerical risk perceptions ($\beta = .14, p = .003$), and higher verbal risk estimates ($\beta = .11, p = .020$) reporting higher levels of breast cancer worry. Illness perceptions explained a further 14% of the variance in breast cancer worry. Holding more chronic timeline beliefs ($\beta = .07, p = .024$), a strong sense or understanding of breast cancer ($\beta = .12, p < .001$), and more negative emotional representations ($\beta = .42, p < .001$) were predictive of higher worry scores.
### Table 7.

**Summary of Hierarchical Regression Analysis for Variables Predicting Breast Cancer Worry**

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<th>Variable</th>
<th>B</th>
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<th>Adj $R^2$</th>
<th>$F_{change}$</th>
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Total $R^2 = 0.44$, Total Adj $R^2 = 0.42$. Significance level: *$p < .05$, **$p < .01$, ***$p < .001$
Factors Predicting Screening Intentions and Breast Self-Examination

A series of Pearson Product moment correlations were conducted to assess which variables to include in the regression analyses predicting screening intentions and breast self-examination (BSE). Confidence in performing BSE, doctors’ recommendations for a mammogram, number of mammograms received, and screening attitudes were all correlated with both screening intentions ($p < .05$) and frequency of BSE ($p < .001$), so were included in the analyses.

A hierarchical multiple regression was conducted to determine the predictors of intention to attend mammography screening (Hypotheses 4-9). Age and family history were entered in the first step. The second step consisted of frequency of breast self-examination (BSE), confidence to perform BSE, whether a doctor had ever recommended a mammogram, and the number of mammograms women had already received. Screening attitudes were also entered in this step. Mean breast cancer worry was included in the third step, whilst risk perceptions and optimism were entered into the fourth step. Illness perceptions were included in the final step.

Analyses revealed that only 9% of the variance was accounted for by the overall model ($F_{(26,489)} = 3.03, p < .001, R^2 = .14, Adj R^2 = .09$). Younger age predicted 6% of the variance ($F_{change (2,513)} = 16.06, p < .001, R^2 = .06, Adj R^2 = .06, \beta = .27, p < .001$), whilst greater confidence in performing BSE ($\beta = .11, p = .026$), and more positive screening attitudes ($\beta = .16, p < .001$) accounted for a further 2% ($F_{change (5,508)} = 3.50, p = .004, R^2 = .09, Adj R^2 = .08$). Breast cancer worry explained a final 1% of the variance ($F_{change (1, 507)} = 10.28, p = .001, R^2 = .11, Adj R^2 = .09, \beta = .18, p = .002$). The inclusion of risk perceptions ($F_{change (6,501)} = 0.59, p = .737, R^2 = .12, Adj R^2 = .09$), and illness perceptions ($F_{change (12,489)} = 1.14, p = .329, R^2 = .14, Adj R^2 = .09$) did not contribute to the overall model.

A hierarchical multiple regression was also conducted to determine the predictors of BSE frequency. Age and family history were controlled for in the first step. The second step consisted of confidence to perform BSE, and the number of mammograms women had already received. Screening attitudes were also entered in this step. Mean breast cancer worry was included in the third step, whilst risk perceptions and optimism were entered into the fourth step. Illness perceptions were included in the final step.
Similar results were found for breast self-examination, with analyses indicating that only 5% of the variance was accounted for by the overall model ($F_{(24,493)} = 2.21, p = .001, R^2 = .10, Adj R^2 = .05$). Greater confidence in performing BSE was the only significant predictor, explaining 2% of the variance ($F_{change (3,512)} = 4.30, p = .005, R^2 = .03, Adj R^2 = .02; \beta = .19, p < .001$). Both breast cancer worry ($F_{change (1,511)} = 4.16, p = .042, R^2 = .03, Adj R^2 = .02$), and risk perceptions ($F_{change (6,505)} = 2.47, p = .023, R^2 = .06, Adj R^2 = .04$) were significant, but the individual beta weights failed to achieve significance. Illness perceptions ($F_{change (12,493)} = 1.64, p = .077, R^2 = .10, Adj R^2 = .05$) failed to contribute to the model. Risk and illness perceptions did not predict screening intentions or breast self-examination. These results therefore partially confirm Hypotheses 5 to 8, and disconfirm Hypothesis 9.

Mediation Analyses

Pearson Product Moment correlations were conducted to assess the relationship between optimism, risk perceptions, and breast cancer worry. Due to the number of measurements of risk perceptions, numerical risk perceptions was chosen to test as a mediator, as it was predictive of breast cancer worry in the hierarchical regressions. As can be seen from Table 6, breast cancer worry was negatively correlated with optimism ($r = -.25, p < .001$), and positively correlated with numerical risk perceptions ($r = .49, p < .001$). Similarly, optimism was negatively correlated with numerical risk perceptions ($r = -.25, p < .001$).

Risk and illness perceptions may not be independent predictors of breast cancer worry, so to test the potential mediating relationship of risk perceptions to illness perceptions and worry, analyses were conducted in line with Baron and Kenny’s method for testing mediation (Hypothesis 10; Table 8; Baron & Kenny, 1986). Age and family history were controlled in the first step of all 4 regressions. In the first regression, illness perceptions were regressed onto risk perceptions and explained 12% of the variance. Only cyclical timeline, chronic timeline, illness coherence and emotional representations predicted risk perceptions, so were included in all further analyses. In the second regression, illness perceptions explained 33% of the variance in breast cancer worry, but cyclical timeline failed to reach significance ($\beta = .04, p = .155$). In the third regression, risk perceptions explained 19% of the variance in worry. In the final regression, risk perceptions and illness perceptions
were entered simultaneously. The overall variance explained by risk and illness perceptions was 38%, with chronic timeline, illness coherence and emotional representations remaining significant predictors. The beta weights for chronic timeline, illness coherence and emotional representations were reduced, although still significant, indicating partial mediation. In applying the Sobel test to assess the significance of intervening intervention effects (Sobel, 1982); the differences between all coefficients were significant ($p < .01$). The results therefore partially confirm Hypothesis 10.

To test if risk numerical perceptions mediate the relationship between optimism and worry (Hypothesis 11), four regressions were conducted in line with Baron and Kenny’s method for testing mediation (Table 9; Baron & Kenny, 1986). Age and family history of breast cancer were controlled for in the first step of each of the regressions. In the first regression, optimism was regressed onto numerical risk perceptions and explained 4% of the variance. In the second regression, optimism explained 5% of the variance in breast cancer worry. In the third regression, risk perceptions explained 19% of the variance in worry. In the final regression, risk perceptions and optimism were entered simultaneously. The overall variance explained was 20%, with both factors remaining significant predictors. The beta weight for optimism was reduced, although still significant (from $\beta = -.23$ to $\beta = -.13$). In applying the Sobel test to assess the significance of intervening intervention effects (Sobel, 1982), the difference between coefficients was significant (Sobel test $= 5.64$, $p < .001$), indicating that risk perceptions partially mediate the relationship between optimism and breast cancer. Hypothesis 11 was therefore partially confirmed.
Chapter 3: Study 1

Table 8.

*Series of Hierarchical Multiple Regressions Assessing the Mediating Role of Numerical Risk Perceptions to the Relationship between Illness Perceptions and Breast Cancer Worry*

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<th>β</th>
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*p < .05, **p < .01, ***p < .001
Table 9.

*Series of Hierarchical Multiple Regressions Assessing the Mediating Role of Numerical Risk Perceptions to the Relationship between Optimism and Breast Cancer Worry*

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<td>0.03</td>
<td>.14***</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Optimism</td>
<td>-0.03</td>
<td>0.01</td>
<td>-.23***</td>
<td>.09</td>
<td>.08</td>
<td>41.35***</td>
<td></td>
</tr>
<tr>
<td><strong>Regression III. Criterion: Breast cancer worry</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Age</td>
<td>-0.30</td>
<td>0.19</td>
<td>-.05</td>
<td>.05</td>
<td>.04</td>
<td>21.33***</td>
<td></td>
</tr>
<tr>
<td>Family history</td>
<td>0.05</td>
<td>0.03</td>
<td>.05</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Risk perception</td>
<td>0.02</td>
<td>0.00</td>
<td>.46***</td>
<td>.24</td>
<td>.24</td>
<td>223.04***</td>
<td></td>
</tr>
<tr>
<td><strong>Regression IV. Criterion: Breast cancer worry</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Age</td>
<td>-0.14</td>
<td>0.20</td>
<td>-.02</td>
<td>.04</td>
<td>.04</td>
<td>15.52***</td>
<td></td>
</tr>
<tr>
<td>Family history</td>
<td>0.04</td>
<td>0.03</td>
<td>.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Optimism</td>
<td>-0.02</td>
<td>0.01</td>
<td>-.13***</td>
<td>.24</td>
<td>.23</td>
<td>100.85***</td>
<td></td>
</tr>
<tr>
<td>Risk perceptions</td>
<td>0.02</td>
<td>0.00</td>
<td>.42***</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < .05, **p < .01, ***p < .001
Chapter 3: Study 1

Differences in Perceptions in Family History and Worry

To ensure an equal sample size across groups, women with a family history of one or more relatives with a diagnosis of breast cancer were grouped together, so that they could be compared against women with no family history. Women with an unknown family history were excluded from the analyses. Using these groups, an independent samples \( t \) test was conducted to assess differences in breast cancer worry in women with a family history \((n = 381)\) and without a family history of breast cancer \((n = 524; \text{Hypothesis 12})\). A significant difference was found, with women with no family history reporting less worry \((M = 2.68, SD = 0.97)\) than women with a family history of breast cancer \((t_{893} = -4.96, p < .001, d = 0.33; M = 3.01, SD = 1.02)\), confirming Hypothesis 13.

The differences between women across illness perceptions and risk perceptions based on family history of breast cancer were examined using a series of one-way between-subjects ANCOVAs (Hypotheses 13-14). The IV was family history and had two levels (family history, no family history). Breast cancer worry was entered as a covariate, as worry was correlated with the illness perception subscales. Means, standard deviations and main effects for family history can be seen in Table 10. A level of significance of \( p < .004 \) was determined using Bonferroni correction to protect against inflated Type I error probability.

In relation to illness perceptions, a significant difference was found for illness coherence \((F_{(1,814)} = 8.16, \eta^2 = .01, p = .004)\). Women with a family history of breast cancer had a higher understanding of breast cancer \((M = 16.51, SD = 4.30)\) than women with no family history \((M = 15.64, SD = 4.33)\). No other differences in illness perceptions were found.

Significant main effects were also found for lifetime numerical risk estimates \((F_{(1,880)} = 33.52, \eta^2 = .03, p < .001)\), verbal risk \((F_{(1,878)} = 74.51, \eta^2 = .06, p < .001)\), vulnerability ratings \((F_{(1,878)} = 37.49, \eta^2 = .03, p < .001)\), and comparative risk estimates \((F_{(1,871)} = 79.55, \eta^2 = .08, p < .001)\). Across all risk estimates, women with a family history reported higher levels of perceived risk than women with no family history. Reported effect sizes were small \((\eta^2 = .01 \text{ to } .08)\). These results partially confirmed Hypothesis 13 that stated that there will be differences in illness perceptions in healthy women with and without a family history of breast. The results also fully confirm Hypothesis 14 that stated that women with a family history
of breast cancer would have higher risk perceptions than women with no family history.
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Table 10.

*Summary of ANCOVA Main Effects for Family History on Illness Perceptions and Risk Perceptions*

<table>
<thead>
<tr>
<th>Condition</th>
<th>No family history</th>
<th>Family history</th>
<th>Total</th>
<th>df</th>
<th>F</th>
<th>p</th>
<th>η²</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M  SD</td>
<td>M  SD</td>
<td>M   SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identity</td>
<td>10.35 3.35</td>
<td>10.41 3.57</td>
<td>10.38 3.44</td>
<td>823</td>
<td>0.03</td>
<td>.855</td>
<td>.00</td>
</tr>
<tr>
<td>Chronic timeline</td>
<td>18.81 3.11</td>
<td>18.79 3.51</td>
<td>18.80 3.28</td>
<td>817</td>
<td>1.20</td>
<td>.274</td>
<td>.00</td>
</tr>
<tr>
<td>Cyclical timeline</td>
<td>12.37 2.17</td>
<td>12.35 2.51</td>
<td>12.36 2.31</td>
<td>812</td>
<td>0.40</td>
<td>.527</td>
<td>.00</td>
</tr>
<tr>
<td>Consequences</td>
<td>23.15 3.06</td>
<td>23.36 3.15</td>
<td>23.24 3.10</td>
<td>817</td>
<td>0.15</td>
<td>.698</td>
<td>.00</td>
</tr>
<tr>
<td>Personal control</td>
<td>20.93 3.60</td>
<td>20.99 3.78</td>
<td>20.95 3.68</td>
<td>819</td>
<td>0.51</td>
<td>.474</td>
<td>.00</td>
</tr>
<tr>
<td>Treatment control</td>
<td>18.74 2.52</td>
<td>18.86 2.67</td>
<td>18.79 2.58</td>
<td>815</td>
<td>1.18</td>
<td>.278</td>
<td>.00</td>
</tr>
<tr>
<td>Illness coherence</td>
<td>15.64 4.33</td>
<td>16.51 4.30</td>
<td>16.00 4.34</td>
<td>814</td>
<td>8.16</td>
<td>.004*</td>
<td>.01</td>
</tr>
<tr>
<td>Emotional representations</td>
<td>18.36 4.71</td>
<td>18.50 4.92</td>
<td>18.42 4.80</td>
<td>811</td>
<td>4.70</td>
<td>.031</td>
<td>.00</td>
</tr>
<tr>
<td>Psychological causes</td>
<td>16.86 4.71</td>
<td>17.04 5.20</td>
<td>16.94 4.91</td>
<td>810</td>
<td>0.12</td>
<td>.731</td>
<td>.00</td>
</tr>
<tr>
<td>Behavioural causes</td>
<td>13.64 2.85</td>
<td>13.44 3.14</td>
<td>13.56 2.97</td>
<td>808</td>
<td>1.57</td>
<td>.211</td>
<td>.00</td>
</tr>
<tr>
<td>External causes</td>
<td>7.51 2.04</td>
<td>7.21 2.17</td>
<td>7.39 2.10</td>
<td>810</td>
<td>5.46</td>
<td>.020</td>
<td>.01</td>
</tr>
<tr>
<td>Medical causes</td>
<td>17.95 2.72</td>
<td>17.84 2.94</td>
<td>17.91 2.81</td>
<td>806</td>
<td>0.41</td>
<td>.524</td>
<td>.00</td>
</tr>
<tr>
<td>Lifetime risk %</td>
<td>32.62 19.51</td>
<td>43.37 22.38</td>
<td>37.16 21.43</td>
<td>880</td>
<td>33.52</td>
<td>.000*</td>
<td>.03</td>
</tr>
<tr>
<td>Five-year risk %</td>
<td>16.73 18.18</td>
<td>21.66 21.43</td>
<td>18.81 19.76</td>
<td>875</td>
<td>4.60</td>
<td>.032</td>
<td>.01</td>
</tr>
<tr>
<td>Verbal estimate</td>
<td>2.35 0.83</td>
<td>2.95 0.95</td>
<td>2.60 0.93</td>
<td>878</td>
<td>74.51</td>
<td>.000*</td>
<td>.06</td>
</tr>
<tr>
<td>Vulnerability estimate</td>
<td>3.47 1.24</td>
<td>4.14 1.31</td>
<td>3.76 1.31</td>
<td>881</td>
<td>37.49</td>
<td>.000*</td>
<td>.03</td>
</tr>
<tr>
<td>Comparative risk</td>
<td>2.62 0.72</td>
<td>3.14 0.83</td>
<td>2.83 0.81</td>
<td>871</td>
<td>79.55</td>
<td>.000*</td>
<td>.08</td>
</tr>
</tbody>
</table>

*Bonferroni correction of p < .004 used to control for Type I error.
Risk Perceptions

A series of one-way between-subjects ANOVAs were conducted to examine differences in psychological variables in women based on their perceived risk of developing breast cancer. Participants’ numerical risk of perceived breast cancer was categorised as optimistic, accurate or pessimistic, based upon numerical risk estimates being within 10% of the medical risk estimate, or Gail score (Gail et al., 1989). Women were categorised as accurate if their scores were within 10% of their Gail score, optimistic if the scores were more than 10% lower than their Gail score and pessimistic if their scores were more than 10% higher than Gail scores. Differences within 10% of Gail measure scores were used previously in Bottorff and colleagues (Bottorff et al., 2004). A level of significance of \( p < .008 \) was determined using Bonferroni correction, to protect against inflated Type I error probability. As can be seen in Table 11, significant differences were found across groups for breast cancer worry, anxiety, and optimism (all \( p < .008 \)), confirming that psychological outcomes differ based on risk perceptions.

Post hoc analyses revealed that women who were pessimistic reported significantly higher breast cancer worry (\( M = 2.95, SD = 1.02 \)) than those with accurate (\( M = 2.33, SD = 1.03, p < .001 \)), or optimistic risk scores (\( M = 2.15, SD = 0.89, p = .044 \)). Similarly, significant differences between women with accurate and pessimistic risk perceptions was found in trait anxiety (\( p = .014 \)). Women with accurate risk estimates reported lower trait anxiety (\( M = 35.94, SD = 10.11 \)) than women with a pessimistic risk estimate (\( M = 40.19, SD = 10.52 \)).

Significant differences were also found in state anxiety in women who were classified as either optimistic or pessimistic (\( p = .029 \)). Women who were optimistic had lower state anxiety scores (\( M = 28.30, SD = 7.62 \)) than women who were pessimistic (\( M = 37.44, SD = 10.77 \)). All differences across groups displayed small to moderate effect sizes (\( \eta^2 = .05 \) to .08).
Table 11. 
*Summary of ANOVAs Conducted Examining Perceived Risk Across Psychological Variables*

<table>
<thead>
<tr>
<th>Condition</th>
<th>Optimistic</th>
<th>Accurate</th>
<th>Pessimistic</th>
<th>df</th>
<th>F</th>
<th>p</th>
<th>$\eta^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Cancer Worry</td>
<td>2.15 0.89</td>
<td>2.33 1.03</td>
<td>2.95 1.02</td>
<td>232</td>
<td>10.60</td>
<td>.000*</td>
<td>.08</td>
</tr>
<tr>
<td>State Anxiety</td>
<td>28.30 7.62</td>
<td>33.85 11.38</td>
<td>37.44 10.77</td>
<td>221</td>
<td>5.15</td>
<td>.006*</td>
<td>.05</td>
</tr>
<tr>
<td>Trait Anxiety</td>
<td>32.75 6.36</td>
<td>35.94 10.11</td>
<td>40.19 10.52</td>
<td>220</td>
<td>5.67</td>
<td>.004*</td>
<td>.05</td>
</tr>
<tr>
<td>Anxiety</td>
<td>5.00 3.66</td>
<td>5.60 4.13</td>
<td>7.07 3.74</td>
<td>203</td>
<td>3.77</td>
<td>.025</td>
<td>.04</td>
</tr>
<tr>
<td>Depression</td>
<td>0.42 0.40</td>
<td>0.37 0.33</td>
<td>0.53 0.33</td>
<td>172</td>
<td>4.49</td>
<td>.013</td>
<td>.05</td>
</tr>
<tr>
<td>Optimism</td>
<td>27.14 4.98</td>
<td>23.48 6.35</td>
<td>20.95 6.90</td>
<td>198</td>
<td>5.27</td>
<td>.006*</td>
<td>.05</td>
</tr>
</tbody>
</table>

*Bonferroni correction of $p < .008$ used to control for Type I error*
Risk perception measurement

The associations between the six types of risk perception measures were also explored. For each of the risk measures, women were categorised as having a low, average, or high perceived risk. Numerical and five year risk scores were calculated by categorising the difference (within 10%) between it and personal Gail scores. Medical risk was calculated by subtracting the average woman’s risk from personal Gail risk and categorising it as higher, accurate, or lower. Verbal and comparative risks were classified according to the verbal descriptors used in the questions. For example, women who reported their risk as above average were classified as higher, whilst those who reported it as below average or below the average woman’s risk, were classified as having lower risk estimates. The risk of women developing breast cancer in Ireland is 1 in 12 (National Cancer Registry, Ireland, 2011), so ratio risk was divided into those who reported ratio as above 1 in 10 as higher, 1 in 10 as accurate, and less than 1 in 10 as lower.

Table 12 shows the frequencies with which women were categorised according to reported risk estimates. For medical risk estimates, as assessed by the Gail model, women either had low or high medical levels of risk of developing breast cancer, with only two women (0.80%) having an average risk of developing breast cancer. In contrast, when measured by numerical risk perceptions, 65.10% of women were categorised as pessimistic, whilst women were more likely to be categorised as accurate (40.70%) or optimistic (43.30%) when measured using verbal risk descriptors.
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Table 12. 
Differences in Categorisation of Participants Based on Six Types of Risk Perception Measures

<table>
<thead>
<tr>
<th>Risk measure</th>
<th>Low</th>
<th>Average</th>
<th>Higher</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Medical risk</td>
<td>146</td>
<td>59.10</td>
<td>2</td>
<td>0.80</td>
</tr>
<tr>
<td>Comparative risk</td>
<td>252</td>
<td>27.60</td>
<td>517</td>
<td>56.70</td>
</tr>
<tr>
<td>Absolute risk</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Numerical risk</td>
<td>10</td>
<td>4.30</td>
<td>72</td>
<td>30.60</td>
</tr>
<tr>
<td>5 year risk</td>
<td>0</td>
<td>0.00</td>
<td>106</td>
<td>45.90</td>
</tr>
<tr>
<td>Ratio risk</td>
<td>291</td>
<td>31.70</td>
<td>165</td>
<td>18.00</td>
</tr>
<tr>
<td>Verbal risk</td>
<td>400</td>
<td>43.30</td>
<td>376</td>
<td>40.70</td>
</tr>
</tbody>
</table>

Note. Measures divided into categories according to responses. Numerical and five year risk scores calculated by categorising the difference (within 10%) of personal Gail scores. Medical risk calculated by subtracting average woman’s risk from personal Gail risk and categorising as higher or lower.

Analyses that included medical risk were conducted on a sub sample of 247 women, as the accuracy of the Gail model is only used for women 35 years or older. Missing values on the numerical risk perception measure led to a final sub sample of 205 women in the subsequent analyses. To examine the association between absolute and comparative risk estimates in healthy women, a Pearson Chi Squared test was conducted (see Table 13). Absolute risk was calculated by determining if participants’ perceived numerical risk was within 10% of the accuracy of their medical risk estimate, as described previously. Comparative risk was determined by subtracting an average woman’s Gail medical risk estimate from her personalised Gail estimate. Those with a higher risk than the average woman (positive value) were categorised as having a pessimistic bias, whilst women who had a lower risk estimate (negative value) were considered to hold an optimistic bias. Women who were accurate were categorised as having an accurate comparative risk. Analyses show that the Chi Square test was significant ($\chi^2 = 16.33, p = .003$). As can be seen
in Table 13, in terms of absolute risk, most women fell into the category of pessimistic (73.70%), whilst in terms of comparative risk; women were much more likely to be categorised as optimistic (43.00%) or accurate (38.00%).

Table 13.

Summary of Frequencies for Absolute Risk and Comparative Bias

<table>
<thead>
<tr>
<th></th>
<th>Absolute Risk</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Optimistic</td>
<td>N</td>
<td>%</td>
<td>Accurate</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Optimistic bias</td>
<td>4</td>
<td>2.00</td>
<td></td>
<td>19</td>
<td>9.30</td>
<td></td>
</tr>
<tr>
<td>Accurate</td>
<td>10</td>
<td>4.90</td>
<td></td>
<td>19</td>
<td>9.30</td>
<td></td>
</tr>
<tr>
<td>Pessimistic bias</td>
<td>0</td>
<td>0.00</td>
<td></td>
<td>2</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>14</td>
<td>6.80</td>
<td></td>
<td>40</td>
<td>19.50</td>
<td></td>
</tr>
</tbody>
</table>

Note. Chi Square test $\chi^2 = 16.33, p = .003$
Discussion

Predictors of Breast Cancer Worry

Although the individual beta weights were not significant, age and family history contributed to breast cancer worry. Younger women reported more worry, confirming previous research (Brain et al., 1999; Cunningham et al., 1998). It should be noted; however, that the variance explained was small. In addition, having a family history of breast cancer was related to more breast cancer worry. The effects of family history on breast cancer worry have been found previously (van Dooren et al., 2005; van Oostrom et al., 2007), indicating that women feel more worried about developing breast cancer in the future if they have affected family members.

Women who reported more general anxiety also reported higher breast cancer worry. This has been highlighted as an issue in the research, as women who display high levels of cancer worry also display high levels of general anxiety (Brain et al., 1999). Lockefeer and De Vries (2012) reported that trait anxiety was the strongest predictor of depression in women with breast cancer. Although this may be the case, trait anxiety was not a predictor, and state anxiety only accounted for 8% of the variance in the current sample, so the results are not due simply to the predisposition of negative mood. Moreover, both trait and state anxiety were moderately correlated with breast cancer worry in the study, highlighting the importance of using specific measures to assess cancer-related worry.

Risk perceptions were influential in determining breast cancer worry. Women with higher absolute risk estimates, measured in both numerical and verbal terms, reported higher levels of worry (Hopwood et al., 2001; Lloyd et al., 1996). Women who consider the risk of developing breast cancer to be high are more likely to be worried about the disease. It is interesting to note that only absolute risk perceptions were predictive of breast cancer worry. Previous research has argued that comparative risk, rather than absolute risk, is more predictive of cancer worry (Lipkus et al., 2005). It may be the case that these risk estimates utilise different information; such that absolute personal risk is associated with negative affect and perceptions of control, whilst comparative risk is related to positive mood (Helweg-Larsen & Shepperd, 2001). This was not possible to assess in the current study, but
further research may help to elucidate the predictive influence of these risk estimates.

Previous research has reported that negative illness perceptions are related to higher rates of worry (Rees et al., 2004). Specifically, healthy women with average risk of developing cancer with a strong illness identity reported more cancer-related distress (Rees et al., 2004). In the present study, illness coherence, chronic timeline, and emotional representations predicted greater worry. This suggests women are more worried if they believe they have a greater understanding of breast cancer, believe it to be a chronic disease, and hold more negative emotional representations. The findings are supportive of the importance of illness perceptions in determining psychological outcomes (Hagger & Orbell, 2003). The different dimensions found to be predictive in the current study in comparison to Rees et al. (2004) are of note. The sample in the Rees et al. study were older, and were receiving counselling for genetic testing for BCRA1/BCRA2 mutations. In addition, in the Rees et al. study, analyses were conducted on the two groups separately; risk and illness perceptions were assessed in women with increased risk and average risk. In contrast, the current study included healthy women in the community, with varying levels of risk. Differences in the illness perceptions were found across these groups, and previous research has suggested that women with and without the disease hold different perceptions of breast cancer (Buick & Petrie, 2002). Further research that assesses illness perceptions in women with varying levels of experience with breast cancer would be useful to help clarify these results.

Risk perceptions partially mediated the relationship between chronic timeline, illness coherence, and emotional representations to breast cancer worry. Women who found breast cancer to be more negative emotionally, considered breast cancer to be a longer condition, and believed they had a greater understanding of breast cancer reported greater worry only when they perceived their risk as high. This is in contrast to the only study that has measured both perceptions of illness and risk previously. Rees and colleagues (2004) reported that illness perceptions and risk perceptions were independent predictors of cancer worry. The SRM was constructed initially to explain a person’s response to a health threat; but was assessed in the present study for its utility in examining how these perceptions relate to perceptions of risk and subsequent worry and screening behaviour. Although women may hold very negative perceptions of breast cancer, it will not lead to increased worry, unless
women also hold high perceptions of risk of developing the disease. Although further work is needed to clarify this relationship, the findings provide tentative support for the parallel processes of the SRM, whereby risk and illness perceptions can be seen as part of the evaluations of the threat of breast cancer, whilst breast cancer worry is an emotional response to the disease (Cameron, 1997). The amount of variance explained in worry was moderate, with the model accounting for 42% of the variance in breast cancer worry. Although perceptions of illness and risk were predictive of breast cancer worry, other variables not included may also have an effect, such as social support or perceived stress. The results are exploratory, so assessment of both risk and illness perceptions in healthy and at-risk groups is necessary.

Intentions to attend a breast cancer screening programme and perform BSE were poorly predicted by the variables in the current study. For mammography screening intentions, age was the most significant predictor, with older women more likely to report intentions to attend screening. Women who are over 50 years of age are at increased risk of developing breast cancer, and display the highest rates of screening (Dawson & Thompson, 1990; Lerman et al., 1993). Despite this, age did not predict a large proportion of the variance; so other factors may be more influential in the decision to attend screening. Barriers to screening may include the inability to schedule time off work to attend screening (George, 2000), or negative perceptions of healthcare services and medical mistrust (Thompson, Valdimarsdottir, Winkel, Jandorf, & Redd, 2004). These socio-demographic and cognitive factors are rarely measured, so it may be useful to examine their influence in future research.

For BSE performance, only 5% of the variance was accounted for by the model. Confidence in performing BSE was the only significant predictor of BSE performance, with higher rates of confidence predicting higher rates of intention to perform BSE. Confidence was generally low in the sample, so future research aimed at increasing BSE behaviour could focus on increasing confidence. It is also important to note that BSE has received less attention than screening, so much less is known about the factors that may affect breast self-examination.

Although accounting for 1% of the variance in screening intentions, breast cancer worry explained no additional variance for BSE, despite the step being significant. Previous studies have found conflicting results between cancer worry and screening behaviour (Hay et al., 2006; Kash, Holland, Halper, & Miller 1992;
Lerman et al., 1996), so further research is needed to clarify the relationship between variables. In confirmation of previous research in healthy women, breast cancer worry was low (Gram & Slenker, 1992; Van Oostrom et al., 2007). This may be due in part to the younger age of the sample. Further research that examines women with high and low breast cancer worry across a broad range of ages may be useful in determining whether it is a predictor of screening intentions and breast self-examination.

Illness beliefs failed to explain any of the variance in intention to attend a screening programme or BSE. Cameron (1997) asserts that perhaps it is not the dimensions of illness beliefs that are predictive of behaviour, but rather a more general belief in vulnerability, or perception of risk. Although it is suggested that women who feel at risk of developing breast cancer may be more likely to attend screening (Katapodi et al., 2004), risk perceptions did not explain any of the variance in intentions, and explained only 2% of the variance in BSE. Risk perceptions do not predict behaviours consistently (Brewer et al., 2007), so further research to examine what other factors play a role is needed (Weinstein, 1988). According to Weinstein (Weinstein, 1988) perceived higher risk is not the only condition for action. Instead it may have more of an indirect effect on screening behaviour (Cameron & Reeve, 2006). Leventhal and colleagues (Leventhal, Kelly & Leventhal, 1999) suggest that the lack of a relationship between behaviour and risk estimates is not surprising. Although risk and illness perceptions seem to be influential, they do not necessarily translate into behaviour. Many other factors are involved in the decision to attend for screening, for example, availability of resources, and previous negative experiences (George, 2000), so the inclusion of components such as these may be useful to examine in the future.

**Family History of Breast Cancer**

Having a family history was related to higher risk perceptions. This has been found in previous research, whereby having a family history of breast cancer increases ones estimates of vulnerability (Bennett et al., 2010; Mellon et al., 2008). Women with a family history were also more likely to have a greater understanding of breast cancer. This is in contrast to previous findings (Rees et al., 2004), that indicated with women at increased risk of developing breast cancer reported less
illness coherence. Although it would seem that women who have a family history would hold cancer in a more negative light, it is conceivable that their experience with the disease provides them with more knowledge, and therefore a more realistic understanding of the illness. No other perceptions of illness differed based on family history. The current sample included healthy women with a broad age range, so not all of these women would be called for routine breast screening. Further research examining the differences in illness perceptions between women with and without a family history of breast cancer that are eligible to attend screening is warranted.

Risk Perceptions as a Mediator

Henderson and colleagues (2008) found that low dispositional optimism was predictive of greater cancer worry in women attending a cancer screening programme. Although optimism was negatively correlated with risk perceptions and breast cancer worry, only risk perceptions predicted breast cancer worry in the current study. Further analyses revealed that risk perceptions partially mediated the relationship between optimism and breast cancer worry. This is in line with McGregor and colleagues (McGregor et al., 2004). Women with low levels of optimism have higher levels of breast cancer worry because they hold higher perceptions of risk. It seems the influence of risk perceptions is exerted through illness perceptions and optimism. This somewhat links in with the SRM, in that risk perceptions and breast cancer worry are part of the parallel processing of health threatening information. Very few studies have attempted to examine both risk perceptions and optimism; so additional research measuring both optimism and risk perceptions will be useful to further our understanding of the relationship between these constructs.

Risk Perceptions

Women who overestimated their risk reported significantly higher state and trait anxiety. Research on risk perceptions and worry has not shown that higher estimates of risk are consistently related to poorer psychological outcomes (Bennett et al., 2010; Nordin, Lidén, Hansson, Rosenquist, & Berglund, 2002). This was supported somewhat in the current study, as depression did not vary across groups,
but differences were found for anxiety. Risk perceptions may reflect a predisposition to experience anxiety, rather than depression. The cross-sectional nature of this study cannot assess this assertion, but these results have implications for the assessment of risk perceptions and worry in the future.

In previous studies, women who were ‘at-risk’ were sampled (Katapodi et al., 2004), whereby women who are attending genetic testing or have a known higher risk of developing cancer were included. Weinstein (1988) has suggested that there is a temporal component to risk estimates, whereby women who are recruited at hospital settings are more aware of their risk, which is reflected in their estimates, whereas the risk in women from the community who have a family history may be minimised (Weinstein, 1999). Despite this, analyses in the present study revealed that women’s classification as optimistic or pessimistic depended on the measure used to assess their perceived risk. Women report a strong pessimistic bias when compared against standards such as the Gail Model, but exhibit a strong optimistic bias when comparing their perceived risk against the average woman (Katapodi et al., 2004; Lipkus et al., 2000). In contrast, women reported accurate or optimistic perceptions when measured using verbal descriptors. Although there is no gold standard for measuring risk perceptions (French & Marteau, 2008; Weinstein, 1999), further research is needed to determine the most appropriate method of assessing risk perceptions, as the current study highlights the methodological issues inherent in this type of research.

Limitations

The current study has a number of limitations. The study was cross-sectional and thus causal relationships cannot be inferred, particularly in terms of assessing the mediating role of risk perceptions. Conducting prospective or longitudinal designs will help clarify the factors that can predict behaviour and the relationship between risk and illness perceptions. Intentions to attend mammography screening and performing BSE were measured using a single item. It is noted, however, that the measures of intention used in this and other studies have not been found to predict actual behaviour (Ajzen & Fishbein, 1980; Ogden, 2003). Objective measures of attendance at screening and performance of BSE are needed to adequately address the relationship between risk and illness perceptions, and these behaviours. The
development of more robust measures is needed to accurately assess these variables in future research.

Family history was not confirmed via medical records, and the level of contact to affected family members was not measured. This broad definition of family history may explain the inconsistent results. In addition, the sample overall was quite young; very few women were aged 50 or more. The current sample may have felt that screening was not relevant to them, so the influence of risk and illness perceptions were not apparent. It would be more useful to focus on screening intentions in an older age group, as they are considered at higher risk of developing breast cancer, and screening may be considered more relevant to this population. At the same time, the current study provides a useful baseline of risk and illness perceptions for these women so that any changes in these variables may be tracked over time.

Strengths

Despite these limitations, the study sample comprised a large number of community-based women, so the findings can be generalised to the wider population. As there is no gold standard with which to measure risk estimates, the current study measured risk perceptions in a number of ways, including a measure of medical risk estimates, to minimise the difficulties in interpreting results that have been seen in previous studies.

The current study is one of the few studies that have measured both risk perceptions and illness perceptions, and is the only study to date that has examined the mediating role of risk perceptions in determining the relationship between illness perceptions and worry in breast cancer. In addition, the current study included measures of family history of breast cancer, optimism, and state and trait anxiety, which are not consistently measured in the research literature, but are important in determining cancer-related worry.

Conclusion

The current study was a cross-sectional, correlational study that examined risk and illness perceptions, and breast cancer worry in a large sample of healthy
women from the community. The study provides novel evidence that both illness and risk perceptions are predictors of breast cancer worry in women from the general population, and provides support for the use of the SRM in determining worry in breast cancer. It is increasingly important to measure both a person’s perception of their risk, as well as their emotional and behavioural responses to the illness threat. The ability of risk and illness perceptions to predict worry fits with the SRM model, and to the identification of women at risk of higher levels of breast cancer worry.

Although they did not predict screening intentions in the present study, further research examining the differences in illness perceptions between women with and without a family history of breast cancer that are eligible to attend screening would be useful. The differences in results in accordance with how risk is measured depict a major limitation to the methodology in risk research. Much care and consideration is needed when choosing what type of measure to use in future research.
STUDY 1b)

A Comparison of Illness Perceptions and Distress in Healthy Women and Women with Breast Cancer

Rationale

Women with a first degree relative with breast cancer often report greater breast cancer worry (Erblich, Bovbjerg, & Valdimarsdottir, 2000; Katapodi, Dodd, Facione, Humphreys, & Lee, 2010; Van Oostrom et al., 2007). Having a family history does not only lead to greater distress and higher risk perceptions, but it may also lead to more negative attitudes to cancer (Hailey et al., 2000). According to the Self-Regulatory model, illness perceptions are formed from a variety of sources of information, including experience of an illness (Leventhal, et al., 1980). In this way, having a family history of breast cancer, or receiving a diagnosis of breast cancer, may impact upon the development of illness perceptions of the disease. Despite their potential importance, there is a paucity of research that has measured illness perceptions in women with and without breast cancer (Buick & Petrie, 2002). One of the few studies to measure differences in illness perceptions in women with and without the disease for differences in breast cancer beliefs was conducted by Buick and Petrie (2002). Healthy women reported more negative beliefs about breast cancer than women with the disease, but the study did not distinguish between those who did and did not have a family history of breast cancer. Women with a family history of cancer hold more realistic expectations of breast cancer (Absetz, Aro, Rehnberg, & Sutton, 2000; Anagnostopoulos & Spanea, 2005; Cunningham et al., 1998; Hopwood, 2000), but their association to cancer worry is unknown. An alternative explanation for the differences in cancer-related beliefs based on varying experience to cancer was proposed by Berrenberg. Developed from the contact hypothesis (Amir, 1969), Berrenberg (1989) developed the familiarity model of cancer attitudes. The model proposes that perceptions vary as a function of experience with a disease. The more experience a person has with cancer, the more positive their attitudes. In this way, healthy women with no family history will have
the most negative attitudes, whilst women with the disease will have the most positive attitudes. A second model, the vulnerability model (Berrenberg, 1989; 1991; Berrenberg, Finlay, Stephan, & Stephan, 2002) states that more contact with cancer patients increases an individual’s sense of personal vulnerability to cancer. The more experience women have with breast cancer, the more salient their risk, and the more negative their attitudes become. In support of the model, women with a first degree relative reported more negative cancer attitudes than women with no family history (Hailey et al., 2000). These results have been replicated by Swords and Groarke (2004), even when experience of breast cancer through extended family and friends was controlled in the analyses. Moreover, the researchers included ratings of contact to those affected with breast cancer, further confirming the validity of the results.

Although promising in explaining differences in attitudes to breast cancer based on experience, very little research has been conducted between healthy women with and without a family history. Even less research has compared these groups to women diagnosed with the disease. The current study, therefore, included healthy women with and without a family history of breast cancer, and included women with the disease for comparison. Furthermore, the inclusion of the three groups allows direct exploration of the usefulness of the models suggested by Berrenberg (1989; 1991), as well as the SRM, in explaining differences in perceptions across groups.

Women who have been diagnosed with breast cancer may hold different illness perceptions because of their recent diagnosis. Distress is high at diagnosis (Meraner et al., 2009), and this level of distress may impact on their perceptions if measured at this time. In contrast, women who are 12 months post-diagnosis report comparable levels of distress to women in the general population (Hou, Law, Yin, & Fu, 2010; van’t Spijker et al., 1997). For this reason, women who were 12 months post-diagnosis were assessed to explore the relationships of illness perceptions and distress at this later time point.

In Study 1a), women from 18 to 70 years were included. There has been some debate regarding the level of breast cancer worry in women based on age. Younger age predicts greater breast cancer worry (Brain et al., 1999; Cunningham et al., 1998; Rees et al., 2004), but differences across age groups are not consistently examined. Differences in worry and illness perceptions may be more pertinent to decisions to attend mammography screening and perform breast self-examination in
women 50 years or older. The present study, therefore, only included women aged 50 years or more, so that the age range was comparable across all 3 groups.

**Aims**

The current study compared women with breast cancer, healthy women with a family history of breast cancer, and healthy women with no family history, on measures of general distress and cancer-related worry. Differences in illness perceptions were also assessed across these groups, to determine if varying experience of breast cancer affects beliefs about the disease, and to assess if the results fit with the models proposed by Berrenberg, and the SRM, in explaining these differences.

**Specific Hypotheses**

15. There are differences in illness perceptions in healthy women with and without a family history of breast cancer, and in women with breast cancer
16. There are differences in cancer-related distress, but not general distress, in healthy women with and without a family history of breast cancer, and in women with breast cancer
Method

Participants and Procedure

The sample comprised 99 women ($M = 55.81$ years, $SD = 4.81$) from the general population, and 60 women ($M = 56.62$ years, $SD = 5.92$) with a confirmed diagnosis of first time non-metastatic breast cancer. The healthy women group was further divided into women with a family history of breast cancer ($N = 37$, $M = 55.83$, $SD = 4.97$), and women without a known family history of breast cancer ($N = 62$, $M = 55.79$, $SD = 4.76$). Women were included if they were 18 years of age or over and able to read and write English. Healthy women were excluded if they had a prior history of breast cancer, and were less than 50 years of age. A summary of demographic information of respondents can be seen in Table 14. The majority of respondents were Anglo-Saxon in their cultural background (98.10%).

Ethical approval was received from the Research Ethics Committees of National University of Ireland, Galway, and University Hospital Galway. Healthy women from the general population were a sub-sample from Study 1a). The procedure for women to take part was the same as Study 1a) (see p. 57). Once data collection was completed, women aged 50 years or older with a family history of breast cancer were selected for the analysis. A total of 99 women were eligible, and were further divided into women with a family history of breast cancer ($N = 37$), or women with no family history of the disease ($N = 62$).

Women with a confirmed diagnosis of breast cancer were approached at the assessment results clinics of BreastCheck, University Hospital Galway and invited to take part. Women who attended the results clinics of BreastCheck, and who were identified as having a confirmed diagnosis of breast cancer were approached by the breast care nurses and told briefly about the study. Women who declined to take part were thanked for their time. Women who expressed an interest in participation received the consent form and a copy of the questionnaire booklet to take home. A stamp-addressed envelope was also provided. Women who returned the questionnaire (this data was only used in Study 2 analyses), were contacted again at 12 months post-diagnosis via post and asked to complete a second questionnaire.
Table 14.
*Summary of Demographic Information for Healthy Women with no Family History (N = 62), Healthy Women with a Family History (N = 37), and Women with Breast Cancer (N = 60)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Healthy Women</th>
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<tbody>
<tr>
<td></td>
<td>No Family history</td>
<td>Family history</td>
<td>Breast Cancer</td>
<td></td>
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<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
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<tr>
<td>Single</td>
<td>9</td>
<td>14.50</td>
<td>6</td>
<td>16.20</td>
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<tr>
<td>Cohabiting</td>
<td>2</td>
<td>3.20</td>
<td>3</td>
<td>8.10</td>
</tr>
<tr>
<td>Married</td>
<td>39</td>
<td>62.90</td>
<td>20</td>
<td>54.10</td>
</tr>
<tr>
<td>Separated</td>
<td>3</td>
<td>4.80</td>
<td>3</td>
<td>8.10</td>
</tr>
<tr>
<td>Divorced</td>
<td>3</td>
<td>4.80</td>
<td>4</td>
<td>10.80</td>
</tr>
<tr>
<td>Widowed</td>
<td>6</td>
<td>9.80</td>
<td>1</td>
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<tr>
<td><strong>Friends/Colleagues</strong></td>
<td></td>
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<tr>
<td>Yes</td>
<td>38</td>
<td>61.30</td>
<td>31</td>
<td>83.80</td>
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<tr>
<td>No</td>
<td>24</td>
<td>38.70</td>
<td>6</td>
<td>16.20</td>
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</table>
Chapter 3: Study 1

Materials and Measures

Basic demographic information was collected, including age and marital status. Family history of breast cancer was measured by a series of questions that asked participants to report whether any immediate female relatives (mother, sister, grandmother) or other female relatives (aunt, niece, cousin) had ever been diagnosed with breast cancer. Women were also asked to indicate if any friends or colleagues had been diagnosed with breast cancer.

Distress

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was used to measure anxiety and depression levels. The State Anxiety subscale of The Spielberger State-Trait Anxiety Inventory (STAI; Spielberger et al., 1970) was used to measure state anxiety. Breast cancer worry in women in the general population was assessed by a series of questions adapted from previous research (Cameron & Diefenbach, 2001; Lipkus et al., 2005). Participants were asked to rate how anxious, fearful, concerned and worried they are about getting breast cancer in their lifetime, from 1 (not at all) to 5 (extremely). These measures were previously outlined in Study 1a) (pp. 62-63).

Cancer-specific worry in women with breast cancer was assessed by a series of questions adapted from previous research (Cameron & Diefenbach, 2001; Lipkus et al., 2005). Participants were asked to rate how anxious, fearful, concerned and worried they are about their diagnosis of breast cancer, from 1 (not at all) to 5 (extremely). Higher scores indicate higher levels of breast cancer worry. Internal reliability for the current sample was deemed appropriate (α = .96), with divergent validity evidenced by its modest association with measures of general anxiety (r = .05, p = .566) and depression (r = .17, p = .047).

Illness perceptions

Illness perceptions were measured using the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002). It was modified so that respondents rated their agreement with statements about breast cancer. This version
was used as it is appropriate for both healthy women and women with breast cancer, and has been used in previous studies examining these groups (Rees et al., 2004). Details of the subscales can be found in Study 1a) (see p. 62). The component structure of the causal items identified in Study 1a) was used for the present study. The subscale consisted of 4 components; psychological causes, which included stress, worry, emotional state, overwork and personality. The second component was labelled behavioural causes, which included smoking, alcohol and diet. The third component included external causes, such as germ or virus, accident or injury, and poor medical care in the past. The final component was labelled as medical causes, which included hereditary, ageing and hormones. Previous research have reported internal reliabilities for the subscales (Cronbach’s $\alpha$) ranging from .75 to .89 (Hagger & Orbell, 2003).
Results

Data Analysis

Pearson Product Moment correlations were conducted to examine the relationships between all variables. One-way between-subjects ANOVAs were conducted to examine the differences in illness perceptions (Hypothesis 15), and distress (Hypothesis 16), in healthy women with and without a family history of breast cancer, and women with breast cancer. A sample size of 156 is required to achieve 80% power for one-way ANOVAs with three groups and a medium effect size (Cohen, 1992). Post-hoc power analyses (Faul et al., 2007) revealed that the sample size of 157 in this study achieved 87.60% power.

Data Preparation

All variables were assessed for normal distribution. Almost all the variables fell within an acceptable range of skew values (< .80). The exceptions to this were state anxiety (skew value = 0.91, SE = .23), and depression, which were positively skewed (skew value = 1.65, SE = .23). Logarithmic transformations were conducted on both variables. Skewness was reduced to acceptable levels for both depression (skew value = 0.14, SE = .22) and state anxiety (skew value = .08, SE = .22), so were used in subsequent analyses. Means and standard deviations reported are from the original data.

Missing value analyses were performed on the data. The percentage of missing data was below 10% for each subscale, with the exception of state anxiety and the identity subscale. Tabachnick and Fidell (2007) advocate the use of a series mean in cases such as these, so missing data were replaced with the series mean for those with less than 10% missing data.

Reliability analyses were conducted for each of the measures. The majority of subscales received Cronbach’s alpha levels of .70 or more, except personal control (α = .69), and treatment control (α = .63). Moreover, three of the causal subscales of the IPQ-R displayed poor reliability: behavioural causes (α = .65), external causes (α = .32), and medical causes (α = .47). Previous research has reported that Cronbach’s alpha is not a useful measure of consistency and reliability when used for subscales
composed of very few items (Cortina, 1993). In the present study, the causal subscales were composed of three to five items, so were therefore included.

Sample Characteristics

Analyses were conducted to assess differences across groups for demographic variables. There were no differences in age ($F(1, 155) = 0.44, p = .645, \eta^2 = .01$), or marital status ($\chi^2 = 12.91, df = 10, p = .229$). Twenty one women with breast cancer (35%) had a family history of the disease, whilst 3 women (5%) were not aware of their family history status. The small numbers across groups; however, did not allow for comparisons in family history across healthy women and women with breast cancer to be conducted.

Correlations between Illness Perceptions and Distress

A series of Pearson Product Moment correlations were conducted to assess the relationships among variables. As can be seen from Table 15, group (healthy women with no family history, healthy women with a family history, women with breast cancer), was not correlated with any of the distress variables, but was positively correlated with chronic timeline ($r = .35, p < .001$), consequences ($r = .33, p < .001$), and negatively correlated with external causes ($r = -.32, p < .001$).

To examine whether experience of friends or colleagues having a diagnosis of breast cancer (yes or no) should be entered as a covariate in subsequent analyses, correlation analyses were conducted with distress and illness perceptions (Table 15). Experience of a having friends or colleagues with a diagnosis of breast cancer was negatively correlated with breast cancer worry ($r = -.22, p = .007$), and positively correlated with chronic timeline ($r = .17, p = .031$), consequences ($r = .21, p = .01$), personal control ($r = .22, p = .006$), treatment control ($r = .18, p = .024$), and medical causes ($r = .26, p = .001$).

Cancer-related worry was positively correlated with emotional representations only ($r = .27, p < .001$). State anxiety was positively correlated with identity ($r = .20, p = .030$), and negatively correlated with illness coherence ($r = -.17, p = .049$). Anxiety as measured by the HADS was positively correlated with chronic timeline ($r = .32, p < .001$), consequences ($r = .16, p = .047$), and emotional representations ($r = .19, p = .015$). Depression was also positively correlated with
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chronic timeline \((r = .31, p < .001)\), consequences \((r = .20, p = .022)\), emotional representations \((r = .18, p = .032)\), and external causes \((r = .17, p = .044)\).
Table 15. Summary of Intercorrelations for Group, Others Diagnosis, Distress, and Illness Perceptions

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<td>1. Group</td>
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<td>2. Others diagnosis</td>
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<td>3. Mean worry</td>
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<td>4. State Anxiety</td>
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<td>5. Anxiety</td>
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<td>6. Depression</td>
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<td>7. Identity</td>
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<td>.10</td>
<td>.20*</td>
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<td>8. Chronic Timeline</td>
<td>.35***</td>
<td>.17*</td>
<td>.00</td>
<td>.15</td>
<td>.32***</td>
<td>.31***</td>
<td>.24**</td>
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<td>9. Cyclical Timeline</td>
<td>.05</td>
<td>.05</td>
<td>-.07</td>
<td>.03</td>
<td>.04</td>
<td>.15</td>
<td>.21*</td>
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<td>10. Consequences</td>
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<td>11. Personal Control</td>
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<td>.18*</td>
<td>-.03</td>
<td>.02</td>
<td>.49***</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Treatment Control</td>
<td>.15</td>
<td>.18*</td>
<td>.00</td>
<td>.02</td>
<td>.11</td>
<td>.15</td>
<td>.01</td>
<td>-.13</td>
<td>-.02</td>
<td>.08</td>
<td>.21**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Illness Coherence</td>
<td>.01</td>
<td>.13</td>
<td>-.14</td>
<td>-.17*</td>
<td>-.03</td>
<td>-.12</td>
<td>-.14</td>
<td>-.20*</td>
<td>-.26***</td>
<td>.06</td>
<td>.32***</td>
<td>.24**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Emotional Reps.</td>
<td>.14</td>
<td>-.12</td>
<td>.27**</td>
<td>.15</td>
<td>.19*</td>
<td>.18*</td>
<td>.21*</td>
<td>.18*</td>
<td>.19*</td>
<td>.12</td>
<td>-.16*</td>
<td>-.06</td>
<td>-.37***</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Psych. Causes</td>
<td>-.07</td>
<td>.09</td>
<td>.07</td>
<td>-.05</td>
<td>.05</td>
<td>.15</td>
<td>.16</td>
<td>.09</td>
<td>.23**</td>
<td>.29***</td>
<td>.35***</td>
<td>.04</td>
<td>.02</td>
<td>.14</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Behav. Causes</td>
<td>-.02</td>
<td>.10</td>
<td>.15</td>
<td>.05</td>
<td>-.00</td>
<td>.14</td>
<td>.13</td>
<td>.15</td>
<td>.19*</td>
<td>.29***</td>
<td>.29***</td>
<td>.16*</td>
<td>.08</td>
<td>.03</td>
<td>.46***</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>17. External causes</td>
<td>-.32***</td>
<td>.03</td>
<td>.09</td>
<td>.14</td>
<td>.07</td>
<td>.17*</td>
<td>.23**</td>
<td>.27***</td>
<td>.14</td>
<td>.01</td>
<td>.12</td>
<td>-.06</td>
<td>-.16*</td>
<td>.09</td>
<td>.33***</td>
<td>.37***</td>
<td>-</td>
</tr>
<tr>
<td>18. Medical causes</td>
<td>-.01</td>
<td>.26***</td>
<td>-.02</td>
<td>-.05</td>
<td>.09</td>
<td>.06</td>
<td>.14</td>
<td>.22**</td>
<td>.18*</td>
<td>.30***</td>
<td>.29***</td>
<td>.18*</td>
<td>.14</td>
<td>.04</td>
<td>.37***</td>
<td>.40***</td>
<td>.20**</td>
</tr>
</tbody>
</table>

Note: Others diagnosis = friends or colleagues diagnosed 1 = yes, 0 = no. Group = 1 = healthy women no family history, 2 = healthy women family history, 3 = women with breast cancer.

*p < .05, **p < .01, ***p < .001
Chapter 3: Study 1

**Prevalence of Distress**

Using the cut-off score of 11 or more of the HADS (Morasso et al., 2001), 14 (22.60%) of the women without a family history, and three (8.10%) women with a family history of breast cancer reported clinical anxiety scores. Eight women (13.30%) with breast cancer reported levels of probable clinical anxiety. A Chi Square Test was conducted to determine whether there was an association between clinical caseness in the anxiety subscale of the HADS and the three groups. The test was not significant, indicating that there was no association between the variables ($\chi^2 = 4.16, df = 4, p = .385$). For depression, only one woman from either of the healthy groups reported clinical levels (1.00%), whilst three (5.00%) women from the breast cancer group reported scores considered to be at a probable clinical level of depression.

**Differences in Illness Perceptions and Distress**

A series of one-way between-subjects ANOVAs were conducted to examine the differences between women across illness perceptions (Hypothesis 15), and distress (Hypothesis 16). The IV was group and had three levels (healthy women with family history, healthy women with no family history, and women with breast cancer). A level of significance of $p < .003$ was determined using Bonferroni correction to protect against inflated Type I error probability. Due to the significant correlations, the experience of having friends or colleagues with a breast cancer diagnosis was entered as a covariate for breast cancer worry, chronic timeline, consequences, personal control, and medical causes. Mean and standard deviations for main effects of family history can be found in Table 16.
**Differences in Illness Perceptions**

A series of one-way between-subjects ANOVAs were conducted to examine differences in illness perceptions across groups (Hypothesis 15). Controlling for the effects of experience of friends or colleagues diagnosis ($F_{(1, 150)} = 6.57, p = .011$), significant differences in illness perceptions across groups were found for chronic timeline ($F_{(2, 150)} = 13.51, p < .001, \eta^2 = .13$), confirming Hypothesis 15. Post hoc analyses revealed that women with breast cancer had lower chronic timeline beliefs ($M = 15.39, SD = 4.03$) than the healthy women groups ($p < .05$).

Significant differences were also found for consequences ($F_{(2, 150)} = 9.26, p < .001, \eta^2 = .11$), after controlling for friends and colleagues diagnosis ($F_{(1, 150)} = 17.33, p < .001$). Women with breast cancer reported higher perceived consequences ($M = 23.50, SD = 3.70$) than either healthy women groups ($p < .01$).

Differences in illness perceptions across groups were also found in external causes ($F_{(1, 156)} = 9.05, p < .001, \eta^2 = .10$). Healthy women with no family history of breast cancer reported higher external causal attributions ($M = 7.83, SD = 1.80$) than women with breast cancer ($M = 6.43, SD = 1.94; p < .001$) and healthy women who had a family history of breast cancer ($M = 6.81, SD = 1.97; p = .025$). Although there were differences across groups for illness coherence ($F_{(1, 156)} = 3.58, p = .03, \eta^2 = .04$), it failed to reach the more stringent level adopted to control for Type I error. All significant differences across groups displayed moderate effect sizes ($\eta^2 = .10$ to .13). The results therefore support Hypothesis 16 that states that illness perceptions differ according to varying experience of breast cancer.

**Differences in Distress**

As can be seen from Table 16, no significant differences were found in anxiety, depression, or state anxiety (Hypothesis 16). Controlling for the main effect of experience of friends or colleagues diagnosis ($F_{(1, 150)} = 3.65, p = .058$), significant differences were found for cancer worry ($F_{(2, 150)} = 9.22, p < .001, \eta^2 = .12$), with women with a family history displaying lower scores on worry ($M = 2.61, SD = 1.09$) than women with breast cancer ($M = 3.57, SD = 0.96$), or healthy women with no family history ($M = 3.45, SD = 1.16; p < .001$). Results fully confirmed Hypothesis 16, which stated that cancer specific-distress, but not general distress, will differ according to varying experience of breast cancer.
Chapter 3: Study 1

Table 16. Summary of ANOVAs Conducting Examining Group Across Distress and Illness Perceptions

<table>
<thead>
<tr>
<th>Condition</th>
<th>No Family history</th>
<th>Family history</th>
<th>Breast Cancer</th>
<th>df</th>
<th>F</th>
<th>p</th>
<th>η²</th>
<th>α</th>
</tr>
</thead>
<tbody>
<tr>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer Worry⁴</td>
<td>3.45</td>
<td>1.16</td>
<td>2.61</td>
<td>1.09</td>
<td>3.57</td>
<td>0.96</td>
<td>150</td>
<td>9.22</td>
</tr>
<tr>
<td>State Anxiety</td>
<td>37.63</td>
<td>10.78</td>
<td>34.59</td>
<td>10.49</td>
<td>37.98</td>
<td>12.32</td>
<td>138</td>
<td>1.12</td>
</tr>
<tr>
<td>Anxiety</td>
<td>6.83</td>
<td>4.00</td>
<td>6.37</td>
<td>3.18</td>
<td>6.29</td>
<td>4.10</td>
<td>156</td>
<td>0.34</td>
</tr>
<tr>
<td>Depression</td>
<td>3.53</td>
<td>2.70</td>
<td>3.12</td>
<td>2.78</td>
<td>3.46</td>
<td>4.11</td>
<td>133</td>
<td>1.39</td>
</tr>
<tr>
<td>Identity</td>
<td>7.85</td>
<td>3.30</td>
<td>8.71</td>
<td>4.20</td>
<td>7.32</td>
<td>3.83</td>
<td>129</td>
<td>1.31</td>
</tr>
<tr>
<td>Chronic Timeline</td>
<td>18.86</td>
<td>3.81</td>
<td>17.39</td>
<td>3.38</td>
<td>15.39</td>
<td>4.03</td>
<td>150</td>
<td>13.51</td>
</tr>
<tr>
<td>Cyclical Timeline</td>
<td>11.63</td>
<td>2.87</td>
<td>11.13</td>
<td>3.55</td>
<td>11.97</td>
<td>3.00</td>
<td>156</td>
<td>0.83</td>
</tr>
<tr>
<td>Consequences ⁴</td>
<td>20.00</td>
<td>5.69</td>
<td>21.23</td>
<td>3.45</td>
<td>23.50</td>
<td>3.70</td>
<td>150</td>
<td>9.26</td>
</tr>
<tr>
<td>Personal Control ⁴</td>
<td>19.52</td>
<td>5.30</td>
<td>21.42</td>
<td>3.88</td>
<td>20.42</td>
<td>3.51</td>
<td>150</td>
<td>1.29</td>
</tr>
<tr>
<td>Treatment Control ⁴</td>
<td>17.49</td>
<td>2.22</td>
<td>17.78</td>
<td>2.02</td>
<td>17.86</td>
<td>2.22</td>
<td>150</td>
<td>1.70</td>
</tr>
<tr>
<td>Illness Coherence</td>
<td>17.27</td>
<td>4.05</td>
<td>19.48</td>
<td>3.79</td>
<td>17.33</td>
<td>4.89</td>
<td>156</td>
<td>3.58</td>
</tr>
<tr>
<td>Emotional Representations</td>
<td>17.50</td>
<td>4.57</td>
<td>16.90</td>
<td>4.42</td>
<td>18.91</td>
<td>4.41</td>
<td>156</td>
<td>2.69</td>
</tr>
<tr>
<td>Psychological Causes</td>
<td>17.57</td>
<td>4.74</td>
<td>17.45</td>
<td>4.54</td>
<td>16.83</td>
<td>3.90</td>
<td>156</td>
<td>0.48</td>
</tr>
<tr>
<td>Behavioural Causes</td>
<td>12.74</td>
<td>2.96</td>
<td>13.10</td>
<td>2.83</td>
<td>12.59</td>
<td>2.79</td>
<td>156</td>
<td>0.36</td>
</tr>
<tr>
<td>External Causes</td>
<td>7.83</td>
<td>1.80</td>
<td>6.81</td>
<td>1.94</td>
<td>6.43</td>
<td>1.94</td>
<td>156</td>
<td>9.05</td>
</tr>
<tr>
<td>Medical Causes ⁴</td>
<td>17.06</td>
<td>2.94</td>
<td>17.28</td>
<td>2.57</td>
<td>17.11</td>
<td>2.73</td>
<td>150</td>
<td>0.02</td>
</tr>
</tbody>
</table>

*significant at $p < .003$ using Bonferroni correction to control for Type I error. ⁴ main effects of group after controlling for friends and colleagues diagnosis as a covariate.
Discussion

Confirming Hypothesis 16, no differences were found across groups for general anxiety, depression, or state anxiety, but there was a difference in specific cancer-related worry. Although Høyer and colleagues (Høyer et al., 2011) reported differences in anxiety and depression between women recently diagnosed with breast cancer and healthy women from the general population, the current study confirms previous research that women’s distress 12 months after a diagnosis of breast cancer was similar to levels of general distress in healthy women (van’t Spijker et al., 1997). The findings suggest that a diagnosis of the disease does not influence general distress.

Although the groups did not differ on general measures of distress, there were significant differences in cancer-related worry. Interestingly, healthy women with a family history of breast cancer had the lowest rates of worry, whilst women with breast cancer and healthy women with no family history reported similar scores. This is in contrast to Rees et al. (2004), who reported less cancer worry in women with average risk of developing breast cancer than women at increased risk. This study was conducted with a sample of women attending genetic counselling for breast cancer, so it is conceivable that they would experience heightened levels of worry. In Study 1a), although conducted with a much younger sample, healthy women with a family history of breast cancer also reported higher cancer worry than women without a family history. In the current study, women with a family history may be attempting to downplay their risk, and therefore report lower worry (Shiloh et al., 2009; Weinstein, 1999). This may also be indicative of accurate knowledge, in that hereditary cancer does not account for a large proportion of breast cancers (Rees et al., 2004), so women with a family history may not be overly distressed about the risk of developing breast cancer. In addition, the current sample included women who were 50 years or older. This group of women may believe that because they have not developed breast cancer at this age, they are less likely to do so in the future. Another possible explanation is that this group may be adhering to recommended screening guidelines, and therefore are less worried about developing the disease. Engaging in screening behaviours may be an effective form of coping with the distress associated with an increased level of risk. Further research
incorporating assessment of risk perceptions and screening behaviours may help to elucidate these relationships in healthy women with a family history.

Women with breast cancer reported that breast cancer is a more acute illness, has more negative consequences, and attributed very few external causes to its development. In contrast, healthy women, regardless of family history, consider it to be more chronic, have less consequences, and are caused by more external factors. There was also a trend for differences in illness coherence across groups, with healthy women with a family history reporting greater understanding of the disease than the other two groups. A significant difference was; however, found in Study 1a), whereby women with more experience of breast cancer through contact of family members, had a greater understanding of the disease. Buick and Petrie (2002) reported differences in perceived control in women with and without breast cancer, but this was not found in the current study. One possible explanation for some of the conflicting findings may be that, unlike the present study, Buick and Petrie (2002) did not assess family history. Although this may have impacted upon the findings, further work is needed to examine whether this was the case.

In previous research, women with an increased risk of developing breast cancer have reported more serious consequences than women at average risk (Rees et al., 2004), whilst others have reported that women with breast cancer hold more serious consequence beliefs than unaffected women (Anagnostopoulos & Spanea, 2005). No differences in consequences were found across healthy groups in the current study, but women with cancer reported more severe consequences compared to the healthy groups. Women with breast cancer reported a more acute timeline in comparison to healthy women. Despite the fact that much research has suggested that family history leads to more negative perceptions of risk and illness (Anagnostopoulos & Spanea, 2005; Buick & Petrie, 2002), it could be argued that for some women, their attitudes become more realistic. Women who have had cancer reported more severe consequences because they have experienced considerable negative consequences of treatment, and believe it to be an acute illness because treatment was effective in treating the disease. More work is needed to assess how illness perceptions differ in these groups, but the results here indicate that women with the disease hold more accurate perceptions than healthy women, regardless of family history.
In contrast to previous research, there were no differences in the causal attributions of psychological or behavioural factors across groups (Buick & Petrie, 2002; Katapodi et al., 2005). In this study, the only exception was for external causes. Healthy women with no family history reported greater external causes of breast cancer, which have been reported in previous research (Wang et al., 2010). Women’s beliefs that external forces are the primary cause of breast cancer may stem from trying to feel less blame for developing cancer; or it may instead be a lack of knowledge as to the risk factors for breast cancer. Risk factors such as hereditary, lifestyle factors, and stress were reported as causal factors by all women, but it seems that healthy women have less knowledge regarding the actual risk factors, and therefore attribute accident, germs, or viruses as causes of breast cancer. This may have implications for adherence and accurate knowledge, as women who report behavioural causes of breast cancer report engaging in health behaviour change (Costanzo, et al., 2011). Healthy women who believe that external factors such as a germ or virus predict breast cancer, may feel that there is nothing they can do to influence the development of the disease, which may in turn lead to poor adherence to breast cancer screening. Although this is speculative, more work is warranted examining the influence of causal attributions and perceptions of the disease on screening behaviours.

The results provide support for the SRM in that differences in illness perceptions are apparent in women with and without breast cancer (Buick & Petrie, 2002). In addition, women who have more coherent perceptions about breast cancer may feel less worried about its development in the future. In contrast, the results only partially support the models proposed by Berrenberg (1989; 1991). Women with breast cancer reported more serious consequences, supporting the vulnerability model, which asserts that beliefs become more negative the more exposure to breast cancer women experience. Healthy women also reported more external causal attributions, which partially supports the familiarity model, which states that women with little or no experience of breast cancer have more negative beliefs. Although comparisons of the models were not tested, the use of the SRM may provide a more useful framework in explaining differences in illness perceptions in this population.

The influence of varying experience of breast cancer on illness perceptions may have direct implications for screening behaviours. For example, women who have a family history may believe they are more susceptible to the disease and may
Chapter 3: Study 1

report illness perceptions such as severe consequences. This in turn may lead women to adhere to screening recommendations (Lostao, Joiner, Pettit, Chorot, & Sandín, 2001). In contrast, women who hold views that are at variance with medical opinion regarding curability and severity and vulnerability to breast cancer (Facione, Giancarlo & Chan, 2000; Silverman et al., 2001), may be less likely to engage in behaviours such as adherence to mammography screening (Lostao et al., 2001; Payne, 1991: Russell et al., 2003). For example, women who endorse stress as a risk factor for breast cancer may be less likely to engage in breast self-examination (Payne, 1991). The finding that women who have a family history of breast cancer, and are therefore at increased risk, have less breast cancer worry, may negatively affect screening adherence. This population are at an increased risk of developing the disease, so this finding is of concern.

Limitations

The current study was cross-sectional, so causal relationships cannot be inferred across variables. Moreover, the sample size was relatively small, with a much smaller group of women with a family history of cancer taking part. In addition, the breast cancer group consisted mainly of women with early stage disease whose cancer was detected during routine mammography in a national breast screening programme. The results would not therefore be generalisable to all women diagnosed with breast cancer in Ireland.

Family history of breast cancer was self-reported, and not confirmed medically. In addition, the level of contact between women and their affected relatives, and the outcome of the family members’ diagnosis, was not assessed. Thewes and colleagues (Thewes, Meiser, Tucker & Schneiden, 2003) reported that caring for a family member with breast cancer and having a parent die from cancer leads to more distress. There may be subsets of the sample that may have had more negative or distressing contact experiences. This could lead to a greater sense of vulnerability, which in turn could influence distress and illness perceptions. This was not assessed in the current study, so results must be interpreted with caution.
Strengths

To the author’s knowledge, this study is the first study to compare women with and without a family history of breast cancer to women with breast cancer. The breast cancer group were 12 months post-diagnosis, so their distress levels were not confounded by treatment-related anxiety. Furthermore, the measures used are well-validated, and support previous findings that family history is related to differences in breast cancer worry and illness perceptions. The groups were matched for age, which has been implicated as a predictor of distress (Brain et al., 1999; Cunningham et al., 1998). Different measures have previously been used across groups, making comparisons difficult (Anagnostopoulos & Spanea, 2005; French, Marteau, Weinman, & Senior, 2004; French, Senior, Weinman, & Marteau, 2001). The current study used the same version of the IPQ-R with all three groups, to avoid the results being artefacts of measurement error. Although level of contact with family members with the disease was not measured, the experience of friends and colleagues with a diagnosis of breast cancer was controlled for in the analyses. Only two other studies have controlled for this variable (Rees et al., 2004; Swords & Groarke, 2004), so its inclusion in the present study provides further evidence that variations in illness perceptions and distress are due to differences in family history, and not affected by other experiences of the disease.

Conclusion

The present study reported that healthy women have different perceptions of breast cancer to women with the disease, but very few differences exist in healthy women with or without a family history. Healthy women’s perceptions of breast cancer may not be accurate representations of the disease. Healthy women with a family history report the lowest levels of breast cancer worry, which may influence the decision to attend routine screening in the future. Programmes aimed at increasing awareness of accurate information about breast cancer may lead to healthy women holding more realistic attitudes to the disease.
Chapter 3: Study 1
CHAPTER 4: STUDY 2

ILLNESS PERCEPTIONS AND COPING IN WOMEN WITH BREAST CANCER

Rationale

A number of constructs have been implicated in predicting distress in women with breast cancer, but there is no consensus as to the variables that are most influential. Although the Self-Regulatory model may explain distress in women with breast cancer, only a handful of studies have assessed illness perceptions in women with breast cancer, and even less have included coping in the analyses. The current study therefore examines the role of illness perceptions and coping in predicting both general and cancer-specific distress, so that the usefulness of the Self-Regulatory Model can be examined.

The majority of illness perception research to date has been cross-sectional, so the present study measured illness perceptions and coping at diagnosis, and examined their influence on distress at diagnosis, and 12 months post-diagnosis, so that their influence could be examined over time. In addition, the current study assessed coping as a mediator to the relationship of illness perceptions and distress in breast cancer. The SRM asserts that coping mediates the relationship between illness perceptions and distress, but there is a paucity of research that has been conducted, and even fewer studies have found evidence for this proposed relationship. One possible explanation for this lack of relationship is that the use of general measures of distress rather than specific measures has been used. The current study assessed both general and cancer-related distress, to examine whether there is a difference across general or more specific measures.

Research assessing distress in women with breast cancer has not consistently controlled for disease factors, despite their noted influence (Burgess et al., 2002). These factors may help to explain distress, so failure to include them may lead to an inaccurate understanding of the most significant predictors of distress. The current
study therefore examined medical variables for their influence on distress in women recently diagnosed with breast cancer, and 12 months post-diagnosis.

Others factors have been implicated in determining distress in women with breast cancer. For example, baseline levels of distress predict greater emotional distress at 6 year follow-up in women with breast cancer (Lam, Shing, Bonanno, Mancini, & Fielding, 2012; Lebel, Rosberger, Edgar, & Devins, 2008). Similarly, perceived stress and number of stressful life events predicted depressive symptoms in 210 women receiving surgical treatment for breast cancer (Golden-Kreutz & Andersen, 2004), and was more influential than coping in predicting adjustment (Groarke et al., 2011). Perceived stress is not always measured, despite its importance as a predictor of distress in women with breast cancer. Perceived stress was therefore included in the present study to assess its relative contribution to distress in women newly diagnosed with breast cancer.

**Aims**

The current study aims to explore the role and relative contribution of demographic, medical, and psychological variables in predicting distress in women with breast cancer at diagnosis, and 12 months post-diagnosis. The study also explores coping as a mediator of the relationship of illness perceptions and distress. An additional aim was to explore changes in anxiety, depression, and perceived stress from diagnosis to 12 months post-diagnosis in women with breast cancer.
Specific Hypotheses

Predictors of Distress

17. At diagnosis, greater perceived stress predicts anxiety, depression, state anxiety, and cancer-related distress
18. At diagnosis, medical variables, illness perceptions and coping strategies predict anxiety, depression, state anxiety, and cancer-related distress
19. At 12 months post-diagnosis, baseline measures of medical variables, illness perceptions, and coping strategies, predicts anxiety, depression, state anxiety, and cancer-related distress

Mediation Analyses

20. Coping strategies mediate the relationship between illness perceptions and cancer-related distress
21. Coping strategies mediate the relationship between illness perceptions and general distress (anxiety, depression)
Chapter 4: Study 2

Method

Participants

The sample comprised 105 women ($M = 56.35$ years, $SD = 5.20$) with a confirmed diagnosis of first time non-metastatic breast cancer. Women were included if they were 18 years of age or over and able to read and write English. Three hundred and ninety one women were given a copy of the questionnaire. Fourteen women refused to take part, and 272 women did not return the questionnaire. A total of 105 were returned (27% response rate). Seventy nine women were eligible to complete questionnaires at 12 months post-diagnosis, and 60 were returned, giving a 76% response rate.

Procedure

The Research Ethics Committees of the National University of Ireland, Galway, and University Hospital, Galway approved the study before data collection commenced. Women with a confirmed diagnosis of breast cancer were approached at the assessment results clinics of BreastCheck and Symptomatic Breast Services, University Hospital Galway, and invited to take part. Women who expressed an interest to find out more information were introduced to the principal investigator by the breast care nurses at a subsequent hospital appointment. The principal investigator gave a short description of the study and then asked patients to read the participant information sheet. Women who expressed an interest in participating received the consent form and a copy of the questionnaire booklet to take home. Participants completed the consent form and questionnaires and returned to the principal investigator in the stamp-addressed envelope provided. Women who returned completed questionnaire booklets were contacted via post 12 months post-diagnosis, and asked to complete measures of anxiety and depression, as well as cancer-related distress and state anxiety.

Materials and Measures

Basic demographic information was obtained, including marital and employment status. Type of surgery, stage of disease, type of diagnosis of breast
cancer, and the type of treatment received (radiotherapy, chemotherapy, hormone therapy), was obtained from medical records of participants. Family history of breast cancer was also measured by a series of questions that asked participants to report whether any female relatives (mother, sister, grandmother, aunt, niece, cousin), and friends or colleagues had ever been diagnosed with breast cancer.

**Perceived stress**

The Perceived Stress Scale (PSS; Cohen, Karmarck, & Mermelstein, 1983) is a 14 item scale designed to measure subjective appraisals of events over the past month. Items consist of rating how often participants have felt or thought in a certain way in the past month. Items are rated from 0 (*never*) to 4 (*very often*). Items are reverse-scored and summed. Higher scores indicate higher levels of perceived stress. In previous studies internal consistency ranged from .75 to .84 (Cohen et al., 1983; Groarke et al., 2011). A single item was also included, that asked participants to specify whether they have experienced any stressful event in the past year.

**Illness perceptions**

Illness perceptions were measured using the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002). Women were asked to rate their agreement to statements about ‘my breast cancer’. All the items are rated on five point Likert scales ranging from 1 (*strongly disagree*) to 5 (*strongly agree*), except for those in the identity dimension. The identity subscale asks women to indicate from a list of 19 symptoms, whether they have experienced any since their breast cancer. Of those symptoms that are reported, respondents are then asked to indicate whether they believe it is a symptom of their breast cancer. Details of the other subscales were previously outlined in Study 1a) (p. 62). Reliabilities for the current sample ranged from $\alpha = .50$ to .87.

Moss-Morris and colleagues (2002) suggest that factor analysis be conducted on the causal subscale of the IPQ-R. Although factor analysis was conducted on the causal subscale for Study 1, it is recommended that factor analyses be conducted within each sample to allow for the most suitable groupings (Dempster et al., 2011), especially across healthy versus cancer populations. A sample size of 300 is required
for factor analysis (Tabachnick & Fidell, 2007), so the current sample was therefore not large enough to conduct these analyses. Previous studies have reported factors such as emotional, behavioural, and externalised causes in oesophageal cancer patients (Dempster et al., 2011), and these have been confirmed in women with breast cancer (McCorry et al., 2012). These factors were therefore used in the current study. Stress or worry, mental attitude, family problems, overwork, emotional state, accident or injury, and personality were included as emotional causes. The behavioural causes subscale included diet, own behaviour, alcohol and smoking. External causes included germ or virus, chance or bad luck, poor medical care in the past, pollution in the environment, ageing, and altered immunity. These causal factors, as reported by McCorry et al. (2012), displayed internal reliabilities ranging from .50 to .79 in the current study.

**Coping**

The Mental Adjustment to Cancer Scale (MAC; Watson et al., 1988) was used to assess coping with a diagnosis of breast cancer. It is a 40-item scale that includes five subscales; fighting spirit, helpless/hopelessness, anxious preoccupation, fatalistic coping, and avoidance. Each item is rated on a four-point scale from 1 (definitely does not apply to me) to 4 (definitely does apply to me). The items for each subscale are summed to give a total subscale score. Higher scores indicate higher levels of the coping style. Reported reliability analyses (Cronbach’s α) range from .64 to .85 (Groarke et al., 2011; Osborne, Elsworth, Kissane, Burke, & Hopper, 1999).

**Distress**

The state subscale of the Spielberger State-Trait Anxiety Scale (STAI; Spielberger et al., 1970) was used. The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was also used. Details of all of these measures were outlined previously in Study 1 (pp. 62-63). Reliabilities for these measures in the current study ranged from .83 to .94.
Cancer-related Distress

At diagnosis, cancer-related distress was assessed by a series of questions adapted from previous research (Cameron & Diefenbach, 2001; Lipkus et al., 2005). Participants were asked to rate how anxious, fearful, concerned and worried they are about their diagnosis of breast cancer, from 1 (not at all) to 5 (extremely). Internal reliability for the current sample was $\alpha = .95$.

At 12 months post-diagnosis, the Impact of Events Scale (IES: Horowitz, Wilner, & Alvarez, 1979) was used to measure cancer-related distress. The measure consists of 15 statements that ask individuals to rate their agreement on a four point Likert scale from 0 (not at all), 1 (rarely), 3 (sometimes), to 5 (often). Seven items relate to intrusion, and 8 items measure avoidance. Items are summed to either give a total cancer-related distress (impact) score, or two subscales; intrusion and avoidance. The present study utilised the total score for analyses. Higher scores indicate higher levels of cancer-related distress. Reported internal consistencies of the measure ranged from .87 to .90 (Groarke et al., 2011; Lebel et al., 2008). The IES was not used at diagnosis, as the distress and impact of the diagnosis may have been difficult to express. The more general questions were therefore used to measure cancer-related distress at diagnosis.
Chapter 4: Study 2

Results

Data Analysis

An independent Samples $t$ test and Chi Squared analyses were conducted to explore differences in responders and non-responders at both time points. Frequencies were conducted to assess the levels of clinical anxiety and depression experienced. Paired Samples $t$ tests were conducted to assess changes in anxiety and depression in women at diagnosis and 12 months post-diagnosis. Pearson Product Moment correlations were conducted to examine the relationships between the predictors and outcome variables. Hierarchical multiple regressions were conducted to examine the relative contributions of demographic, medical, and psychological variables as predictors of distress in women with breast cancer at diagnosis (Hypotheses 17-18) and 12 months post-diagnosis (Hypothesis 19). Finally, mediation analyses were conducted to assess whether coping is a mediator of the relationship of illness perceptions and cancer-related and general distress (Hypotheses 20-21).

To achieve 80% power when conducting regressions with five predictors and a medium effect size, a sample size of at least 90 participants is required (Cohen, 1992). Power analyses revealed that the current study achieved 59.20% power with 105 participants for the regressions at diagnosis, and achieved 54.50% power at 12 months post-diagnosis. The current sample of 57 participants for the $t$ tests to assess differences in distress over time achieved 95.90% power.

Data Preparation

Missing value analyses were performed on the data. The percentage of missing data was below 10% for each subscale at baseline, and less than 5% for 12 months post-diagnosis, so missing data were replaced with the series mean (Tabachnick & Fidell, 2007). Three of the 60 women at 12 months post-diagnosis had considerable missing data (greater than 60%), so were excluded from all analyses.

All variables were assessed for normal distribution. Almost all the variables fell within an acceptable range of skew values ($< .80$). The exceptions to this were the identity subscale (skew value = 0.93, $SE = .24$), and depression (skew value =
0.80, \(SE = .24\), which were positively skewed. Logarithmic transformations were conducted, and reduced the skew values (-0.09, \(SE = .28\) and skew = -0.37, \(SE = .26\) respectively), so were used in subsequent analyses. At 12 months post-diagnosis, depression (skew value = 2.32, \(SE = .34\)), perceived stress (skew value = 0.83, \(SE = .34\)), and state anxiety (skew value = 1.09, \(SE = .34\)) were all positively skewed. Logarithmic transformations were conducted, and reduced the skew values for depression (skew value = 0.75, \(SE = .34\)), and state anxiety (skew value = 0.35, \(SE = .34\)), but not for perceived stress (skew value = -0.87, \(SE = .34\)). The transformed depression and state anxiety were therefore included in subsequent analyses. The original data for perceived stress was included, but non-parametric tests were used for analysis with this variable. Means and standard deviations reported are from the original data.

Reliability analyses were conducted for each of the measures (as can be seen in Table 17). At diagnosis, the majority of subscales received Cronbach’s alpha levels of .70 or more, with the exception of helplessness/hopelessness (Cronbach’s \(\alpha = .68\)), anxious preoccupation (Cronbach’s \(\alpha = .60\)), and fatalistic coping (Cronbach’s \(\alpha = .62\)). Reliability analyses were not conducted on the avoidance coping subscale, as it contains only one item. At 12 months post-diagnosis, all the variables displayed Cronbach’s alpha levels of .70 or more.
Table 17
Means, Standard Deviations and Ranges of the Psychological Variables Measured at Diagnosis and 12 Months Post-Diagnosis

<table>
<thead>
<tr>
<th>Variable</th>
<th>Range</th>
<th>M</th>
<th>SD</th>
<th>α</th>
<th>Potential</th>
<th>Actual</th>
<th>Skew</th>
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<tbody>
<tr>
<td>Age</td>
<td>40-77</td>
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<td>5.27</td>
<td>-</td>
<td>-</td>
<td>4-20</td>
<td>.31</td>
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<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer-related Distress</td>
<td>4-20</td>
<td>14.20</td>
<td>4.10</td>
<td>.95</td>
<td>0-21</td>
<td>0-20</td>
<td>.01</td>
</tr>
<tr>
<td>General Distress (HADS)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>0-21</td>
<td>8.03</td>
<td>4.62</td>
<td>.89</td>
<td>0-21</td>
<td>0-20</td>
<td>.27</td>
</tr>
<tr>
<td>Depression</td>
<td>0-14</td>
<td>3.99</td>
<td>3.72</td>
<td>.85</td>
<td>0-21</td>
<td></td>
<td>.80</td>
</tr>
<tr>
<td>State Anxiety (STAI)</td>
<td>4-16</td>
<td>47.64</td>
<td>13.98</td>
<td>.94</td>
<td>20-80</td>
<td>21-75</td>
<td>.03</td>
</tr>
<tr>
<td>Perceived Stress (PSS)</td>
<td>8-46</td>
<td>22.32</td>
<td>7.83</td>
<td>.83</td>
<td>0-52</td>
<td>8-46</td>
<td>.52</td>
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<tr>
<td>Illness Perceptions (IPQ-R)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identity</td>
<td>0-17</td>
<td>2.25</td>
<td>2.29</td>
<td>.72</td>
<td>0-9</td>
<td>.93</td>
<td></td>
</tr>
<tr>
<td>Chronic Timeline</td>
<td>6-25</td>
<td>12.57</td>
<td>4.82</td>
<td>.87</td>
<td>6-30</td>
<td>6-25</td>
<td>.44</td>
</tr>
<tr>
<td>Cyclical Timeline</td>
<td>4-20</td>
<td>8.92</td>
<td>3.05</td>
<td>.85</td>
<td>4-20</td>
<td>4-16</td>
<td>-.08</td>
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<tr>
<td>Consequences</td>
<td>9-30</td>
<td>19.67</td>
<td>4.87</td>
<td>.76</td>
<td>6-30</td>
<td>9-30</td>
<td>-.36</td>
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<tr>
<td>Personal Control</td>
<td>10-30</td>
<td>22.08</td>
<td>4.37</td>
<td>.77</td>
<td>6-30</td>
<td>10-30</td>
<td>-.32</td>
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<td>Treatment Control</td>
<td>5-25</td>
<td>21.96</td>
<td>2.68</td>
<td>.71</td>
<td>5-25</td>
<td>14-25</td>
<td>-.63</td>
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<tr>
<td>Illness Coherence</td>
<td>8-25</td>
<td>17.86</td>
<td>4.43</td>
<td>.81</td>
<td>5-25</td>
<td>8-25</td>
<td>-.22</td>
</tr>
<tr>
<td>Emotional</td>
<td>6-30</td>
<td>19.23</td>
<td>4.97</td>
<td>.83</td>
<td>6-30</td>
<td>6-30</td>
<td>-.42</td>
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<tr>
<td>Representations</td>
<td>6-27</td>
<td>14.14</td>
<td>4.61</td>
<td>.79</td>
<td>6-30</td>
<td>6-27</td>
<td>.20</td>
</tr>
<tr>
<td>Emotional Causes</td>
<td>5-25</td>
<td>10.61</td>
<td>3.97</td>
<td>.75</td>
<td>5-25</td>
<td>5-25</td>
<td>.73</td>
</tr>
<tr>
<td>Behavioural Causes</td>
<td>8-24</td>
<td>14.87</td>
<td>3.45</td>
<td>.50</td>
<td>6-30</td>
<td>8-24</td>
<td>-.02</td>
</tr>
<tr>
<td>External Causes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coping (MAC)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fighting Spirit</td>
<td>31-58</td>
<td>46.04</td>
<td>5.22</td>
<td>.78</td>
<td>16-64</td>
<td>31-58</td>
<td>.10</td>
</tr>
<tr>
<td>Helpless/Hopelessness</td>
<td>6-18</td>
<td>9.73</td>
<td>2.82</td>
<td>.68</td>
<td>6-24</td>
<td>6-18</td>
<td>.29</td>
</tr>
<tr>
<td>Anxious Preoccupation</td>
<td>12-33</td>
<td>21.98</td>
<td>3.78</td>
<td>.60</td>
<td>9-36</td>
<td>12-33</td>
<td>-.18</td>
</tr>
<tr>
<td>Fatalistic Coping</td>
<td>10-27</td>
<td>18.24</td>
<td>3.52</td>
<td>.62</td>
<td>8-32</td>
<td>10-27</td>
<td>-.24</td>
</tr>
<tr>
<td>Avoidance</td>
<td>1-4</td>
<td>1.98</td>
<td>0.81</td>
<td>-</td>
<td>1-4</td>
<td>1-4</td>
<td>-.37</td>
</tr>
<tr>
<td><strong>12 Months Post-Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer-related Distress (IES)</td>
<td>0-65</td>
<td>25.55</td>
<td>16.76</td>
<td>.89</td>
<td>0-80</td>
<td>0-80</td>
<td>.35</td>
</tr>
<tr>
<td>General Distress (HADS)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>0-17</td>
<td>6.33</td>
<td>4.10</td>
<td>.86</td>
<td>0-21</td>
<td>0-17</td>
<td>.62</td>
</tr>
<tr>
<td>Depression</td>
<td>0-19</td>
<td>3.12</td>
<td>3.74</td>
<td>.92</td>
<td>0-21</td>
<td>0-19</td>
<td>.32</td>
</tr>
<tr>
<td>State Anxiety (STAI)</td>
<td>21-80</td>
<td>37.35</td>
<td>13.24</td>
<td>.94</td>
<td>20-80</td>
<td>21-80</td>
<td>1.09</td>
</tr>
<tr>
<td>Perceived Stress (PSS)</td>
<td>5-47</td>
<td>20.22</td>
<td>8.10</td>
<td>.85</td>
<td>0-52</td>
<td>5-47</td>
<td>.83</td>
</tr>
</tbody>
</table>

Note. HADS = Hospital Anxiety and Depression Scale; STAI = State-Trait Anxiety Inventory; PSS = Perceived Stress Scale; IPQ-R = Revised Illness Perception Questionnaire; MAC = Mental Adjustment to Cancer Scale; IES = Impact of Events Scale.
Sample Characteristics

Differences in responders and non-responders

Diagnosis

An Independent Samples t test was conducted to assess differences in age in women who did and did not respond. There were no differences in age between those women who did and did not participate ($t_{(366)} = -0.72, p = .474$). Chi Squared analyses were conducted to examine differences in stage of disease, type of surgery, and type of treatment. Non-responders were more likely to have received a mastectomy, or required both a lumpectomy and subsequent mastectomy than responders ($\chi^2 = 32.96, df = 4, p < .001$). In addition, responders were more likely to have invasive ductal carcinoma (IDC) or mixed carcinoma type, but less DCIS than non-responders ($\chi^2 = 14.49, df = 4, p = .006$). There were no differences in stage of disease ($\chi^2 = 8.51, df = 4, p = .075$).

Twelve months post-diagnosis

At 12 months post-diagnosis, Independent Samples t tests were conducted to assess differences in women who did ($n = 57$) and did not respond ($n = 22$). At 12 months post-diagnosis, women who did not respond reported higher depression ($t_{(27.42)} = 2.53, p = .017$) at diagnosis than women who did respond.

Medical characteristics

As can be seen from Table 18, the most common form of cancer diagnosed in those who responded was invasive ductal cancer (IDC) and mixed invasive/non-invasive ductal cancer (IDC with DCIS). Women required either a lumpectomy (54.30%), mastectomy (7.60%) or had a mastectomy after a lumpectomy (7.60%). The majority of women had early stage disease; almost 42% of women had Stage I disease, with only 8.60% of women having Stage III or IV disease. Radiotherapy was frequently prescribed as a treatment (77.10%), along with hormone or endocrine therapy (87.60%). Only 31.40% of the sample required chemotherapy as a treatment for their disease. Almost three quarters of the sample (74.30%) had experience of friends of colleagues with breast cancer, whilst 34.30% had a known family history of breast cancer.
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Not all women completed measures of marital and employment status. Of those who did, the majority of women were married (79.10%), with a small proportion of women separated or divorced (9.30%). As can be seen in Table 19, almost half of the sample were working (45.50%), working in the home (21.80%), or retired (23.60%).

Table 18.
Summary Frequencies of Medical Variables for Responders and Non-Responders at Diagnosis

<table>
<thead>
<tr>
<th>Variable</th>
<th>Responders</th>
<th>Non-Responders</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td><strong>Diagnosis</strong> (N = 384)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DCIS/LIN/LCIS</td>
<td>10</td>
<td>9.50</td>
</tr>
<tr>
<td>IDC</td>
<td>40</td>
<td>38.10</td>
</tr>
<tr>
<td>IDC and DCIS</td>
<td>32</td>
<td>30.50</td>
</tr>
<tr>
<td>ILC / ILC and LIN</td>
<td>9</td>
<td>8.60</td>
</tr>
<tr>
<td>Mixed carcinoma</td>
<td>14</td>
<td>13.30</td>
</tr>
<tr>
<td><strong>Surgery</strong> (N = 391)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lumpectomy</td>
<td>57</td>
<td>54.30</td>
</tr>
<tr>
<td>Lumpectomy and clearance</td>
<td>7</td>
<td>6.70</td>
</tr>
<tr>
<td>Mastectomy</td>
<td>8</td>
<td>7.60</td>
</tr>
<tr>
<td>Lumpectomy and re-excisions</td>
<td>19</td>
<td>18.10</td>
</tr>
<tr>
<td>Lumpectomy and Mastectomy</td>
<td>8</td>
<td>7.60</td>
</tr>
<tr>
<td>Missing</td>
<td>6</td>
<td>5.70</td>
</tr>
<tr>
<td><strong>Stage of Disease</strong> (N = 391)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 0</td>
<td>12</td>
<td>11.40</td>
</tr>
<tr>
<td>Stage IA, IB</td>
<td>44</td>
<td>41.90</td>
</tr>
<tr>
<td>Stage II, IIB</td>
<td>30</td>
<td>28.60</td>
</tr>
<tr>
<td>Stage III, IIIB, IIIC, IV</td>
<td>9</td>
<td>8.60</td>
</tr>
<tr>
<td>Unknown</td>
<td>10</td>
<td>9.50</td>
</tr>
</tbody>
</table>

*Note.* DCIS = ductal carcinoma in situ; LIN = lobular in-situ neoplasia; LCIS = lobular carcinoma in situ; IDC = invasive ductal carcinoma; ILC = invasive lobular carcinoma
Table 19.

*Summary Frequencies of Demographic, Stress, and Causal Attribution Variables*

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Marital Status (N = 86)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>4</td>
<td>4.70</td>
</tr>
<tr>
<td>Cohabiting</td>
<td>1</td>
<td>1.10</td>
</tr>
<tr>
<td>Married</td>
<td>68</td>
<td>79.10</td>
</tr>
<tr>
<td>Separated / Divorced</td>
<td>8</td>
<td>9.30</td>
</tr>
<tr>
<td>Widowed</td>
<td>5</td>
<td>5.80</td>
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<tr>
<td><strong>Employment (N = 55)</strong></td>
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<tr>
<td>Full-time</td>
<td>14</td>
<td>25.50</td>
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<tr>
<td>Part-time</td>
<td>11</td>
<td>20.00</td>
</tr>
<tr>
<td>Working in the home</td>
<td>12</td>
<td>21.80</td>
</tr>
<tr>
<td>Unemployed</td>
<td>5</td>
<td>9.10</td>
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<tr>
<td>Retired</td>
<td>13</td>
<td>23.60</td>
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<tr>
<td><strong>Stressful life events (other than cancer diagnosis)</strong></td>
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<td></td>
</tr>
<tr>
<td>No stressful event</td>
<td>60</td>
<td>57.10</td>
</tr>
<tr>
<td>Bereavement</td>
<td>10</td>
<td>9.50</td>
</tr>
<tr>
<td>Health – physical and mental</td>
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<td>4.80</td>
</tr>
<tr>
<td>Family – conflict, illness</td>
<td>12</td>
<td>11.40</td>
</tr>
<tr>
<td>Financial and work problems</td>
<td>6</td>
<td>5.80</td>
</tr>
<tr>
<td>Social stresses – weddings, moving</td>
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<td>1.90</td>
</tr>
<tr>
<td>Multiple stressors</td>
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<td>9.50</td>
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<tr>
<td><strong>Causal Attributions (IPQ-R)</strong></td>
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<td></td>
</tr>
<tr>
<td>Emotional state</td>
<td>24</td>
<td>22.90</td>
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<tr>
<td>Family problems</td>
<td>27</td>
<td>25.70</td>
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<tr>
<td>Mental attitude</td>
<td>13</td>
<td>12.40</td>
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<tr>
<td>Overwork</td>
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<td>Personality</td>
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<td>6.70</td>
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<tr>
<td>Smoking</td>
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<td>16.20</td>
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<tr>
<td>Alcohol</td>
<td>7</td>
<td>6.70</td>
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<tr>
<td>Diet, eating habits</td>
<td>17</td>
<td>16.20</td>
</tr>
<tr>
<td>Pollution in the environment</td>
<td>31</td>
<td>29.50</td>
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<tr>
<td>Accident or injury</td>
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<td>6.70</td>
</tr>
<tr>
<td>Germ or virus</td>
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<tr>
<td>Poor medical care in the past</td>
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<td>Hormones</td>
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<td>37.10</td>
</tr>
<tr>
<td>Chance or bad luck</td>
<td>46</td>
<td>43.80</td>
</tr>
<tr>
<td>Own behaviour</td>
<td>12</td>
<td>11.40</td>
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</tbody>
</table>

*Note.* Multiple causal attributions were endorsed by participants.  
IPQ-R = Revised Illness Perception Questionnaire.
Prevalence of Distress

Almost 58% of women reported no stressful event in the past year. Of those who did report a stressful experience, the most common stressors were family illness and conflict (11.40%), bereavement (9.50%), and multiple stressors (9.50%). The five most commonly attributed causes to breast cancer were stress or worry (58.10%), hormones (44.80%), chance or bad luck (43.80%), hereditary (37.10%), and ageing (35.20%). Pollution in the environment (29.50%), family problems (25.70%), and emotional state (22.90%) were also commonly attributed as causes of breast cancer.

Using the cut off score of 11 adopted in previous research in the HADS (Morasso et al., 2001), participants were assessed for the prevalence of clinical levels of anxiety and depression over time. Thirty two women (30.50%) reported clinical levels of anxiety, and seven women (6.70%) reported clinical depression scores (see Table 20). At 12 months post-diagnosis, only eight women (14.00%) reported clinical anxiety levels, whilst 3 women (5.30%) displayed depression scores above the cut-off. The differences between categories at baseline and 12 month follow-up were significant for both anxiety ($\chi^2 = 12.28, df = 4, p = .015$) and depression ($\chi^2 = 15.31, df = 4, p = .004$).

The mean score of cancer-related distress at diagnosis was 14.20 ($SD = 4.10$). Thirty eight women scored 16 or more (36.20%), indicating high levels of cancer-related distress. At 12 months post-diagnosis, the mean score of cancer-related distress, as measured by the IES, was 25.55 ($SD = 16.76$). A cut off score of 33 has been suggested as a way to measure impact in the IES (Creamer, Bell, & Failla, 2003). In the current sample, 17 women (29.80%) reported scores of 33 or more.
Table 20.

**Summary of Frequencies for Cut-off Scores for Anxiety and Depression (HADS) at Diagnosis and 12 Months Post-Diagnosis**

<table>
<thead>
<tr>
<th>Distress</th>
<th>Diagnosis</th>
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<tr>
<td></td>
<td>Anxiety</td>
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<td>Anxiety</td>
<td>Depression</td>
<td>Anxiety</td>
<td>Depression</td>
<td>Anxiety</td>
<td>Depression</td>
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<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
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<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Mild (0-7)</td>
<td>48</td>
<td>45.70</td>
<td>84</td>
<td>80.00</td>
<td>38</td>
<td>66.70</td>
<td>52</td>
<td>91.20</td>
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<tr>
<td>Moderate (8-10)</td>
<td>25</td>
<td>23.80</td>
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<td>13.30</td>
<td>11</td>
<td>19.30</td>
<td>2</td>
<td>3.50</td>
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<tr>
<td>Probable (&gt;11)</td>
<td>32</td>
<td>30.50</td>
<td>7</td>
<td>6.70</td>
<td>8</td>
<td>14.00</td>
<td>3</td>
<td>5.30</td>
</tr>
<tr>
<td>Total</td>
<td>105</td>
<td>100.00</td>
<td>105</td>
<td>100.00</td>
<td>57</td>
<td>100.00</td>
<td>57</td>
<td>100.00</td>
</tr>
</tbody>
</table>

**Prevalence of distress over time**

A series of paired samples $t$ tests were conducted to examine differences in anxiety, depression, and perceived stress over time. Significant differences were found for the HADS anxiety subscale ($t_{(56)} = 2.36$, $p = .022$, $d = 0.63$), and state anxiety ($t_{(56)} = 6.13$, $p < .001$, $d = 1.64$). As can be seen in Figure 2, anxiety decreased from diagnosis ($M = 7.83$, $SD = 4.09$), to 12 months post-diagnosis ($M = 6.45$, $SD = 4.29$). Similarly, state anxiety scores reduced from diagnosis ($M = 48.91$, $SD = 14.52$), to 12 months post-diagnosis ($M = 37.81$, $SD = 13.54$). No differences were found for depression ($t_{(56)} = 0.29$, $p = .770$), or perceived stress ($z = -1.66$, $p = .097$) over time.
**Figure 2.** Differences in anxiety and depression scores (HADS), state anxiety (STAI), and perceived stress (PSS) from diagnosis to 12 months post-diagnosis.
Predictors of Psychological Adjustment at Diagnosis

A series of Pearson Product Moment Correlations were conducted with demographic and disease variables and distress. Type of surgery was positively correlated with cancer-related distress \( (r = .24, p = .021) \), anxiety \( (r = .22, p = .025) \), and depression \( (r = .27, p = .007) \). No other demographic or disease variables were significant, so type of surgery only was controlled for in the regression analyses.

Hierarchical multiple regressions were conducted to determine the influence of demographic and medical variables, perceived stress, illness perceptions and coping on distress (cancer-related distress, anxiety, depression; Hypotheses 17-18). Emotional representations were excluded from analyses due to the high correlations with all the outcome variables \( (r = .45 \) to \( .72) \).

Multicollinearity was assessed with the remaining variables by first examining bivariate correlations between the predictor variables (see Table 21). Correlations ranged from \( .22 \) to \( .67 \), indicating that multicollinearity was not present in the sample. VIF scores ranged from 1.28 to 3.22 (tolerance scores ranged from 0.31 to 0.78) for diagnosis, and ranged from 1.08 to 1.85 (0.62-0.92) for 12 months post-diagnosis. These scores are within the acceptable ranges (Hutcheson & Sofroniou, 1999), so all the predictors were included in the analyses.

Type of surgery was controlled for in the first step, whilst perceived stress was entered in the second step. The order of the other variables in the regression were determined using the SRM model; which asserts that illness perceptions contribute to coping, which then determine adjustment (e.g. distress). For this reason, illness perceptions were entered in the third step, and coping was included in the final step. A summary of regressions can be seen in Table 22.
## Chapter 4: Study 2

#### Table 21. Summary of Intercorrelations for Psychological Variables at Diagnosis

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<thead>
<tr>
<th></th>
<th>1</th>
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<td>8. Treatment Control</td>
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*p < .05, **p < .01, ***p < .001
Table 22. Hierarchical Multiple Regressions of the Influence of Type of Surgery, Perceived Stress, Illness Perceptions, and Coping on Anxiety, Depression, and Cancer-related Distress at Diagnosis

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Depression (HADS)</th>
<th>Anxiety (HADS)</th>
<th>State Anxiety (STAI)</th>
<th>Cancer-related Distress</th>
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<tr>
<td></td>
<td>β</td>
<td>F change</td>
<td>Adj. R² change</td>
<td>β</td>
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<td>(1) Type of Surgery</td>
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<td>7.92**</td>
<td>.07</td>
<td>.13</td>
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<tr>
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<td>Illness coherence</td>
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<td>Total Adj R²</td>
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Note. HADS = Hospital Anxiety and Depression Scale; STAI = State-Trait Anxiety Inventory. *p < .05, **p < .01, ***p < .001.
Chapter 4: Study 2

As can be seen in Table 22, all of the models were significant, confirming Hypotheses 17-18. Type of surgery predicted 5% of the variance in cancer-related distress ($\beta = 0.20, p = .020$), and 7% of the variance in depression ($\beta = 0.22, p = .005$). Although the overall steps were significant, the type of surgery beta weight for anxiety ($\beta = 0.13, p = .102$) failed to reach significance. For all variables, women who required a mastectomy had higher scores for all outcome variables compared to women who received a lumpectomy.

Perceived stress predicted between 9-33% of the variance across outcome measures. Higher scores on perceived stress predicted greater anxiety ($\beta = 0.37, p < .001$) and depression ($\beta = 0.37, p < .001$). Perceived stress also predicted greater state anxiety ($\beta = 0.19, p < .001$).

Illness perceptions also accounted for a proportion of the variance in cancer-related distress (29%), anxiety (7%), and state anxiety (19%). Having greater illness coherence predicted lower cancer-related distress ($\beta = -0.23, p = .022$), and less state anxiety ($\beta = -0.30, p = .006$). Behavioural causes also predicted less cancer-related distress ($\beta = -0.32, p = .005$). Illness perceptions also predicted 14% of the variance in depression. Higher personal control beliefs ($\beta = 0.29, p = .002$), and a stronger illness identity ($\beta = 0.28, p = .024$), predicted higher levels of depression.

Coping explained 5% of the variance in cancer-related distress. Higher levels of fighting spirit predicted lower cancer-related distress ($\beta = -0.23, p = .032$), whilst high levels of anxious preoccupation predicted greater cancer-related distress ($\beta = 0.33, p = .006$). No other variables were predicted by coping.
Predictors of Distress from Diagnosis to 12 Months Post-diagnosis

A series of Pearson Product Moment Correlations were conducted to assess relationships between variables at 12 months post-diagnosis. No demographic or medical variables were correlated with the adjustment measures, so were not included in subsequent analyses. As can be seen in Table 23, identity was correlated with depression \((r = .23, p = .019)\), and state anxiety \((r = .20, p = .039)\). Cyclical timeline and chronic timeline were both correlated with anxiety, depression and state anxiety. Illness coherence was correlated with state anxiety \((r = -.25, p = .009)\), and total cancer-related distress \((r = -.23, p = .020)\). For the coping subscales, only anxious preoccupation was correlated with state anxiety \((r = .30, p = .002)\), and total cancer-related distress \((r = .28, p = .003)\). No other variables were correlated with any of the outcomes measures.

A series of hierarchical regressions were conducted to determine the influence of baseline measures of distress, illness perceptions and coping on anxiety, depression, and total cancer-related distress at 12 months post-diagnosis (Hypothesis 19). The total score of the IES was used as a measure of total cancer-related distress. Due to the small sample size, it was inappropriate to include all variables as predictors without comprising on power. Only variables that correlated with the outcome variables were included in the regressions. This has been suggested as a way to avoid studies being underpowered (Hulbert-Williams, Neal, Morrison, Hood, & Wilkinson, 2011; Tabachnick & Fidell, 2007).

As can be seen in Table 24, baseline measures of distress were controlled for in the first step. In line with the correlations conducted, identity, cyclical timeline, chronic timeline, and coherence were included in the second step, and anxious preoccupation coping was entered into the third step. The overall models for anxiety \((F (6, 50) = 2.30, p = .049, R^2 = .22, Adj \ R^2 = .12)\), and depression were significant \((F (6, 50) = 2.31, p = .048, R^2 = .22, Adj \ R^2 = .12)\), each explaining 12% of the variance. The steps that included baseline measures of distress were significant for anxiety \((F \text{ change } (1, 55) = 5.44, p = .023, R^2 \text{ change } = .09, Adj \ R^2 \text{ change } = .07)\), and depression \((F \text{ change } (1, 55) = 9.50, p = .003, R^2 \text{ change } = .15, Adj \ R^2 \text{ change } = .13)\). Despite this, none of the beta weights reached significance.

The overall model for state anxiety was also significant \((F (6, 50) = 4.83, p = .001, R^2 = .37, Adj \ R^2 = .29)\). The only significant predictor of state anxiety was state
Chapter 4: Study 2

anxiety at baseline ($F_{\text{change}} (1, 55) = 24.49, p < .001, R^2_{\text{change}} = .31, \text{Adj } R^2_{\text{change}} = .29$), with higher state anxiety scores at diagnosis predicting greater state anxiety 12 months post-diagnosis ($\beta = .41, p = .015$).

The overall model for total cancer-related distress was significant ($F_{(5, 56)} = 2.92, p = .022, R^2 = .22, \text{Adj } R^2 = .15$). Greater levels of anxious preoccupation at diagnosis predicted greater total cancer-related distress ($F_{\text{change}} (1, 51) = 7.21, p = .01, R^2_{\text{change}} = .11, \text{Adj } R^2_{\text{change}} = .11, \beta = .39, p = .01$). Illness perceptions did not predict any of the outcome variables, partially confirming Hypothesis 19.
Table 23.

Summary of Correlations between Illness Perceptions and Coping with Distress at 12 Months Post-Diagnosis

<table>
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<tr>
<th></th>
<th>1</th>
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*Note. Inter-correlations between illness perceptions and coping can be seen in Table 21. *p < .05, **p < .01, ***p < .001
Table 24.
Hierarchical Multiple Regressions of the Influence of Baseline Measures of Distress, Illness Perceptions and Coping on Anxiety, Depression, and Cancer-related Distress at 12 months Post-Diagnosis

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<th>Anxiety (HADS)</th>
<th>State Anxiety (STAI)</th>
<th>Cancer-related Distress (IES)</th>
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<td>Adj. R² change</td>
<td>β</td>
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<td>.20</td>
<td>.21</td>
<td>.24</td>
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<td>Cyclical Timeline</td>
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<td>.09</td>
<td>.23</td>
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<td>.25</td>
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<tr>
<td>(3) Coping</td>
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<td>.02</td>
<td>.02</td>
<td>.25</td>
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<td>Anxious Preoccupation</td>
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</tr>
<tr>
<td>Total Adj R²</td>
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<td>.18</td>
<td>.29</td>
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</table>

Note. HADS = Hospital Anxiety and Depression Scale; STAI = State-Trait Anxiety Inventory; IES = Impact of Events Scale. *p < .05, **p < .01, ***p < .001.
Mediation Analyses

Mediation analyses, in line with Baron and Kenny (1986), were conducted to assess whether coping is a mediator of the relationship between illness perceptions and cancer-related and general distress (Hypotheses 20-21). Correlations were first conducted with anxiety, depression, cancer-related distress, illness perceptions and coping. As can be seen in Table 21, greater cancer-related distress was related to greater illness identity (r = .21, p = .028), a more chronic timeline (r = .39, p < .001), cyclical timeline (r = .44, p < .001), more severe consequences (r = .41, p < .001), less illness coherence (r = -.44, p < .001), and more use of anxious preoccupation as a coping strategy (r = .55, p < .001). Fatalistic coping (r = .37, p < .001), and helplessness and hopelessness were also correlated with cancer-related distress (r = .30, p = .002), but were not correlated with all the illness perceptions. Subsequently, mediation analyses were conducted to assess the role of anxious preoccupation as a mediator to illness perceptions (identity, chronic and cyclical timeline, consequences and illness coherence), to cancer-related distress (see Table 25).

Cancer-related distress

Type of surgery was controlled for in the first step of each of the regressions. In the first regression, illness perceptions were regressed onto anxious preoccupation and explained 33% of the variance. In the second regression, cyclical timeline, consequences and coherence explained 34% of the variance in cancer-related distress. In the third regression, anxious preoccupation explained 27% of the variance in cancer-related distress. In the final regression, illness perceptions and anxious preoccupation were entered simultaneously. The overall variance explained was 38%. The beta weight for consequences (from β = .32 to β = -.14) and cyclical timeline (from β = .26 to β = .12) were no longer significant. In applying the Sobel test to assess the significance of intervening intervention effects (Sobel, 1982), the difference between coefficients for consequences (Sobel test = 3.07, p = .002), and cyclical timeline were significant (Sobel test = 2.37, p = .002) indicating that the relationship between consequences, cyclical timeline and cancer worry were fully mediated by anxious preoccupation. The beta weights for illness coherence were reduced, but still significant. The differences between coefficients was significant,
however (Sobel test = 2.21, $p = .027$) indicating partial mediation, confirming Hypothesis 20, whereby anxious preoccupation fully mediated the relationship between illness perceptions (cyclical timeline, consequences) and cancer-related distress. Anxious preoccupation also partially mediated the relationship between illness coherence and cancer-related distress.

**Anxiety**

Mediation analyses were also conducted to assess whether anxious preoccupation was a mediator of the relationship between illness perceptions (identity, chronic and cyclical timeline, consequences and illness coherence) and anxiety, as measured by the HADS (see Table 26). Cyclical timeline, consequences, and coherence predicted 33% of the variance in anxious preoccupation. Chronic timeline and coherence predicted 22% of the variance in anxiety. Anxious preoccupation explained 29% of the variance in anxiety. The inclusion of anxious preoccupation with illness perceptions in the final model predicted 33% of the overall variance. The beta weight for chronic timeline became non-significant but in applying the Sobel test to assess the significance of intervening intervention effects (Sobel, 1982), the difference between coefficients was not significant (Sobel test = 0.29, $p = .775$). The beta weight for coherence also became non-significant, with Sobel test showing significant intervening intervention effects (Sobel test = 2.24, $p = .025$), partially confirming Hypothesis 21, whereby anxious preoccupation fully mediated the relationship between illness coherence and anxiety.

**Depression**

Mediation analyses were also conducted to assess whether anxious preoccupation was a mediator of the relationship between illness perceptions (identity, chronic and cyclical timeline, consequences and illness coherence) and depression, but were not significant (data not shown).
Table 25.

Series of Hierarchical Multiple Regressions Assessing the Mediating Role of Anxious Preoccupation to Illness Perceptions and Cancer-related Distress

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<th>SE</th>
<th>β</th>
<th>( R^2 )</th>
<th>( Adj , R^2 )</th>
<th>( Adj , R^2 )</th>
<th>( F ) change</th>
<th>( F ) change</th>
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*p < .05, **p < .01, ***p < .001
### Table 26.
*Series of Hierarchical Multiple Regressions Assessing the Mediating Role of Anxious Preoccupation to Illness Perceptions and Anxiety*

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*p < .05, **p < .01, ***p < .001
Discussion

A number of women reported clinical levels of anxiety, but very few women reported clinical levels of depression at diagnosis. The results are in line with previous research that suggests that a diagnosis of breast cancer is characterised by greater anxiety than depression (Høyer et al., 2011; Thuné-Boyle et al., 2012). In addition, levels of anxiety decreased from diagnosis to 12 months post-diagnosis. Research has consistently shown that anxiety decreases over time, falling to levels comparable to that of the general population by 12 months (Carlson et al., 2011; Carver et al., 1993; van’t Spijker et al., 1997). The group was not very depressed at diagnosis, so very little change was possible in these variables over time. It should be noted that the majority of the sample was comprised of women who were diagnosed through a screening programme. Breast cancer screening is still very new in Ireland, and the psychosocial consequences of receiving a diagnosis of cancer when attending routine screening is not known in an Irish sample. Although the current study provides some insight into distress in this group, the sample also consisted of women who had symptomatic disease. Very little research has examined how screen-detected breast cancer patients differ from those who were self-detected (e.g. Henselmans et al., 2010; Iwatani, Matsuda, Kawabata, Miura, & Matsushima, 2012; Lockefeer & De Vries, 2012), and the experience may be different (Farmer, 2000). Given the sample size, it was not possible to assess any potential differences in the current sample, but further work would be useful to examine the adjustment to a cancer diagnosis in these two groups.

Predictors of Distress at Diagnosis

Type of surgery predicted depression and cancer-related distress, with those requiring a mastectomy having higher scores for both variables. This has been found in previous research, with those requiring more invasive treatment reporting greater levels of distress (Burgess et al., 2002; Lauzier et al., 2010; Trimmel et al., 2005; van’t Spijker et al., 1997). Although type of surgery does predict distress, it does not account for much of the variance, indicating that other factors are more influential in determining distress.
Greater perceived stress predicted greater anxiety and depression. Previous studies have asserted that global stress is a predictor of distress in women with breast cancer (Golden-Kreutz et al., 2005). In the study conducted by Groarke and colleagues (2011), perceived stress was a stronger predictor of distress than coping. The findings suggest that although factors such as illness perceptions and coping may have an influence, the experience of recent stressful life events can also impact upon distress in women when diagnosed with breast cancer. The results underscore the importance of the inclusion of appraisal of stress in women with breast cancer, as previous stressful events may influence how women respond to a subsequent diagnosis.

More negative illness beliefs predicted greater distress. Higher levels of identity predicted greater levels of depression. Holding a strong illness identity predicted greater psychological morbidity across a wide range of conditions (Kaptein et al., 2006; Vaughan et al., 2003). It has also been consistently shown to be a strong predictor in cancer patients (Llewellyn et al., 2006; Scharloo et al., 2005), as well as women with breast cancer (McCorry et al., 2012). Moreover, holding a strong illness identity was predictive of distress at 12 months follow-up in women with breast cancer (Millar et al., 2005). This suggests that illness identity is a consistent predictor of greater distress; interventions that attempt to modify identity may be beneficial in improving psychological outcomes in women with breast cancer.

Greater perceived control has typically predicted less distress in breast cancer (McCorry et al., 2012; Millar et al., 2005). In contrast, in the current study, higher personal control beliefs predicted higher levels of depression at diagnosis. Stiegelis and colleagues (2003) reported higher levels of control to be predictive of less depression, and this has been replicated in other research (Helder et al., 2002; Sawicki, Sellers, & Robinson, 2011). There are a number of possible explanations for this surprising finding. Women who perceive themselves as having high levels of personal control over the development of breast cancer may be more distressed when receiving a diagnosis. Similarly, women who perceive high levels of personal control may feel an added pressure to cope well with the disease, and to exert a high degree of influence. In contrast, having to relinquish control of a situation may also lead to greater depression. According to models of control, if individuals attempt to exert control over an uncontrollable situation, they will experience greater distress (Taylor 1983). For example, in people with rheumatoid arthritis (Schiaffino et al., 1998),
having a strong sense of cure and personal responsibility predicted higher levels of depression. It may be that women who perceive high levels of personal control over their illness were more depressed because they were unable to exert influence on an uncontrollable situation. Newsom, Knapp, and Schulz (1996) reported that in patients with recurrent cancer, having high levels of onset control were predictive of higher depression levels. Believing that one can control the onset of cancer leads to greater depression when cancer recurs. This highlights the differences between what Thompson and colleagues (Thompson et al., 1993) refer to as central or consequences-related control. Central control is the belief that an event can be avoided or minimised, whilst consequence-related control is the belief that the side effects of an event, such as treatment, can be successfully controlled (Thompson & Collins, 1995). The mean level of depression was low in this sample; however, so further work is needed to explain this result. Furthermore, perceived control over illness specific-events, such as treatment side effects, may be important to examine in this population in the future.

Having greater illness coherence predicted lower cancer-related distress, and state anxiety. Women with breast cancer feel less distressed if they have a clear sense of the disease and feel that they understand it more. Illness coherence may overlap with perceived knowledge of cancer, and this may be directly influenced by how the diagnosis is communicated to patients (Farmer, 2000). Clear descriptions and explanations of the disease may lead to higher levels of illness coherence, which in turn may predict lower distress. Although this may be a possible explanation for the relationship, communication style and knowledge were not included; more work examining the relationship between communication and distress is needed to address how it can influence illness coherence.

The most common causal attributions reported in the current study were stress or worry, hormones, ageing, hereditary, and chance or bad luck. Stress is considered a common cause of breast cancer (Panjari, Davis, Fradkin, & Bell, 2012), despite a lack of evidence for this causal relationship (Duijts, Zeegers, & Borne, 2003; McKenna, Zevon, Corn, & Rounds, 1999). The causal attributions of ageing, hormones, and hereditary have been reported in other samples of women with breast cancer (Wang et al., 2010). In the current study, behavioural causes such as smoking and diet were not highly endorsed, but other causes such as pollution were reported as causal factors. Despite this, only beliefs in behavioural causes predicted less
distress. Behavioural factors are often considered to contribute to the development of breast cancer (Parrott, Silk, & Condit, 2003), and are often related to greater distress (Costanzo et al., 2005; Silverman et al., 2001). Ostroff, Hay, Schantz, and Maher (2000) noted that in a sample of people at risk of developing head and neck cancer, personal health habits were considered to encompass almost all of the factors that decrease risk factors for cancer, whereas they only comprised a small number of the risk-increasing factors. It may be that higher beliefs in behavioural causes may lead to the perception that future recurrences can be avoided by engaging in behaviour change (Christensen et al., 1999), therefore reducing current levels of distress. Further research examining causal attributions and their relation to changes in behaviour over the course of the illness will illustrate how they may be used to develop interventions for positive behaviour change.

Coping explained a small percentage of the variance in cancer-related distress at diagnosis. Higher levels of fighting spirit predicted less cancer-related distress. Fighting spirit has consistently been shown to be a predictor of less distress in women with breast cancer (Epping-Jordan et al., 1999; Groarke et al., 2011). Cancer-related distress was also predicted by higher levels of anxious preoccupation. Previously, Groarke and colleagues (2011) reported that greater use of anxious preoccupation predicted greater depression and negative affect at pre-surgery in breast cancer, whilst predicting greater anxiety at pre- and post-surgery. Anxious preoccupation has been related to greater distress in both newly diagnosed patients and long-term survivors of breast cancer (Boyes et al., 2009; Wang et al., 2012). This is in line with the established literature that contends that active coping styles such as fighting spirit are adaptive, whilst passive or emotion-focused styles such as anxious preoccupation are maladaptive (Carver et al., 1993; Stanton & Snider, 1993). Reductions in anxious preoccupation may lead to decreased distress and better psychological outcomes. Moreover, women who ruminate on their illness are at much higher risk of developing distress than women who do not engage in anxious preoccupation. The use of measures such as anxious preoccupation to identify women who may be at greater risk of experiencing distress in the future may therefore be valuable.
Predictors of Distress over Time

The findings at diagnosis suggest that illness perceptions are better predictors of distress than coping in women recently diagnosed with breast cancer. This supports previous arguments by researchers (Jopson & Moss-Morris, 2003) that coping strategies are not as important as illness perceptions in predicting adaptation to illness. Analyses at 12 months post-diagnosis; however, provide a different picture. Distress scores at diagnosis were by far the most important predictors over time, while illness perceptions did not predict distress. This is similar to findings of Groarke et al. (2005) in their two-year longitudinal study of people with rheumatoid arthritis. They found that illness perceptions explained more variance in concurrent indices of adjustment, but did not explain any of the variance over time. One possible explanation is that illness perceptions reflect current distress, rather than predict it. The over-reliance on cross-sectional measurement does not allow for an examination of this explanation, but warrants further attention in more longitudinal designs.

Controlling for distress at diagnosis, the only significant predictor at 12 months post-diagnosis was anxious preoccupation. It accounted for 9% of the variance in cancer-related distress. The negative effects of this coping strategy are well-documented (Boyes et al., 2009; Wang et al., 2012), and were previously found to be predictors of distress in a sample of Irish women with breast cancer (Groarke et al., 2011). The ability of anxious preoccupation to predict cancer-related distress at 12 months post-diagnosis indicates that although coping may not be as important as illness perceptions in determining distress at diagnosis, its influence may be exerted over time. Illness perceptions are generally stable over time (Weinman et al. 1996; Moss-Morris et al., 2002) so their influence may wane as the disease course progresses. Coping, however, may be a continuous process, so it may continue to influence distress. This reflects the cyclical nature of the SRM, whereby illness perceptions and coping predict distress, while over time; distress can predict illness perceptions and coping. More work is needed to clarify when the factors begin to exert their influence, but the control of baseline distress in the present study allows for the conclusion that coping predicts one aspect of cancer-related distress over time.
Mediation Analyses

Analyses revealed that anxious preoccupation fully mediated the relationship between cyclical timeline and consequences to cancer-related distress. Anxious preoccupation also partially mediated the influence of illness coherence to cancer-related distress. Coping did not mediate the relationship between illness perceptions and depression. The influence of beliefs about the cyclical nature of breast cancer, and the perceived understanding or coherence of the disease, is determined by the level of anxious preoccupation women engage in. The impact of perceived consequences of the disease to cancer-related distress is also affected by the levels of anxious preoccupation. Anxious preoccupation also fully determined the influence of illness coherence on levels of general anxiety. These results confirm previous research that suggests illness perceptions and coping are related (Hagger & Orbell, 2003). This is one of the few studies to demonstrate the presence of mediation (Gould et al., 2010; Rutter & Rutter, 2002), as previous research has found no such relationship (Dorrian et al., 2009; Kaptein et al., 2006; McCorry et al., 2012). The findings suggest that modification of coping may lead to changes in the relationship between illness perceptions and distress. This may have implications for future interventions. Illness perceptions may be difficult to modify (McCorry et al., 2012), whereas coping strategies may be more amenable to change. Interventions that target coping, and in particular the use of anxious preoccupation, could be employed to reduce distress, influence illness perceptions, and promote greater adjustment.

Coping may not be important as a means to reduce distress in women at diagnosis, but becomes more important when specific aspects of the disease course are experienced. For example, coping may be more important than illness beliefs when dealing with the side effects of treatment. Although research contends that illness perceptions are greater predictors of distress in women with breast cancer than coping (Millar, et al., 2005), there is a need to conduct more prospective and longitudinal studies to understand the relationship between variables. The longitudinal data in this study, although limited by the small sample size, provides some understanding of the relationships between the components of the Self-Regulatory model.
Limitations

The modest sample size limited the analyses that could be conducted. This was especially true for the 12 months post-diagnosis data. Many variables were not included as to do so would have resulted in a lack of power. The sample was not representative of all women diagnosed in the West of Ireland as the vast majority of the sample had screen-detected disease. The results are therefore only generalisable to women who are diagnosed through screening. The emergence of standardised national screening programmes will reduce the number of self-detected cancers; however, so the results are important for determining how this group respond to a cancer diagnosis.

The response rate was poor, and was partly due to the fact that women were asked to complete the questionnaires before commencing treatment. As women had surgery within four weeks of being diagnosed, and some women had surgery within a week of receiving their diagnosis, many individuals were simply unable to complete the questionnaire before this time. Although the inclusion criteria in this case were stringent, it was necessary to gain an insight into women’s perceptions and distress before commencement of treatment. Data collection occurred in two separate clinics, BreastCheck clinics, and the Symptomatic Breast Services clinics; and a slightly different protocol was required for each of these. This led to variances in the number of women from each centre being recruited. The BreastCheck clinics were designed so that all eligible women diagnosed were invited to participate as part of standard procedure in the clinics. In contrast, women from the Symptomatic Breast Services were first identified by the breast care nurses, and then the researcher was required to make contact with these women. This led to greater delays in provision of the questionnaire, and a much smaller number of women being eligible to take part before commencement of treatment. Recruitment of cancer patients in research is challenging, and although the poor response rate was disappointing, all women were consecutive women attending Breast clinics with a confirmed diagnosis of breast cancer. Moreover, based on the available information, there were no differences on age, or stage of disease between responders and non-responders. Women who were more depressed were less likely to participate at 12 months post-diagnosis, so the levels of distress at 12 months may be underestimated,
and the results should be treated with caution, due to an over-representation of women with lower distress scores.

Previous studies have assessed coping as a predictor of cancer-related distress (Lebel et al., 2008). Despite this, one further limitation of the present study is that anxious preoccupation and cancer-related distress, as measured by the IES, may be conceptually similar, so the use of anxious preoccupation as a predictor of cancer-related distress should be considered with caution. Despite this, the measures were not highly correlated, so were included in the analyses.

Although illness perceptions and coping were assessed for their influence on distress over time, they were only measured at diagnosis, limiting the ability to test changes in these variables over time. Additionally, due to the paucity of validated measures, coping appraisal was not included, so the full Self-Regulatory model was not examined for its ability to predict distress in women with breast cancer.

Recent studies have suggested that alternative forms of analysis should be conducted when measuring the predictive utility of illness perceptions (Clatworthy, Hankins, Buick, Weinman, & Horne, 2007). Examining particular patterns of illness perceptions may be more meaningful and more predictive of health outcomes than assessing dimensions independently (Schiaffino & Revenson, 1995). Cluster analysis is considered an effective way to determine the importance of illness perceptions (Graham, Rose, Hankins, Chalder, & Weinman, 2012). The original model suggests that illness perceptions are arranged into sets or clusters, so cluster analysis is a particularly useful tool to examine the combined effect of specific illness perceptions on distress (Clatworthy et al., 2007). Although potentially useful for the current research, especially in addressing the small sample size, it was not conducted. Illness perception research has predominantly employed regression analyses (Kaptein et al., 2006; Keeling, Bambrough, & Simpson, 2012; Millar et al., 2005). The current research therefore utilised regression analyses using the components as separate predictors to enable comparisons of results with previous research. Future work; however, can use cluster analysis to assess the influence of illness perceptions on distress in this population.
Strengths

The current study controlled for various demographic and disease factors. Many of these variables have not been assessed in the same study, particularly perceived stress. It predicted a considerable amount of the variance in general and cancer-specific distress at diagnosis, so the inclusion of this measure should be more consistently employed. A specific measure of coping was used, addressing some of the problems that are inherent with using general measures. In particular, both general and specific measures of cancer-related distress were included, giving further validation of the results to this sample.

The inclusion of longitudinal data is of value as research to date has been predominantly cross-sectional (Bradley, et al., 2001; Lichtenstein Jørgensen et al., 2009; Llewellyn et al., 2007; Rozema et al., 2008). The use of a longitudinal design allowed for control of the baseline levels of distress when assessing the predictors of distress at 12 months post-diagnosis, minimising the potential confound of shared variance across predictors. At the same time, this is one of only a handful of studies that has included measures of illness perceptions and coping in a sample of women with breast cancer. Mediation analyses were conducted, allowing for further examination of how illness perceptions and coping relate to one another within the context of the Self-Regulatory model. The present study is also the first study to confirm that coping mediated the relationship between illness perceptions and distress in breast cancer. Although much more work is warranted, it provides insight into how these variables interact with one another within the Self-Regulatory model.

Conclusions

The present study reported that distress in women with breast cancer decreases from diagnosis, to 12 months post-diagnosis. Distress at diagnosis is predicted by illness perceptions, and to a lesser extent, coping. In contrast, at 12 months post-diagnosis, baseline scores of distress and coping were the only significant predictors. The results indicate that although illness perceptions are better predictors of distress at diagnosis, coping explained more variance at 12 months post-diagnosis. In addition, anxious preoccupation mediated the relationship between illness perceptions and distress. Further work is needed to assess the importance of these variables at discrete stages of the illness. Despite this, the results
are indicative of illness perceptions and coping as important predictors of distress over the first 12 months after a diagnosis of breast cancer.
CHAPTER 5: STUDY 3

COPING WITH CHEMOTHERAPY FOR BREAST CANCER

Rationale

The previous study (Study 2) focused on the predictive ability of illness perceptions and coping to explain distress in women with breast cancer at diagnosis and 12 months post-diagnosis. Although explaining some of the variance, coping was not a strong predictor of distress. This may be due to the fact that measures of coping, regardless of whether they are general or specific assessments of coping, are still measuring how participants respond to a diagnosis of breast cancer, rather than to specific aspects of the disease. A diagnosis of breast cancer poses a number of distinct challenges across the illness trajectory, and coping may change in response to these challenges (Wang et al., 2012). In addition, coping may become more important when specific aspects of the disease are experienced. Focusing on one aspect of the disease and assessing the specific coping strategies used to deal with this event, therefore, may be more useful than assessing coping to a diagnosis in more general terms.

Chemotherapy is one of the most stressful aspects of a cancer diagnosis (Jacobsen et al., 1993), and some research has focused on how women deal with the side effects of treatment. Coping with chemotherapy has not been consistently assessed, but the limited research in the area (Bussell & Naus, 2010; Manne et al., 1994; Shapiro et al., 1997; Waldrop, O’Connor, & Trabold, 2011), indicates that women engage in a variety of coping responses to deal with the symptoms of chemotherapy treatment. The current study, therefore, assessed coping responses towards chemotherapy as a treatment for breast cancer.

Ways to measure specific coping strategies to deal with chemotherapy have not been adequately developed. Although some quantitative studies have assessed coping in women during chemotherapy (Shapiro et al., 1997), qualitative methods may be a helpful way to fully understand the subjective experience of breast cancer.
treatment. Qualitative research is useful in this context, as questions can be tailored to how women respond to specific aspects, rather than taking a more global view of coping. This approach has been previously used to examine specific forms of coping such as anticipatory coping for hair loss during chemotherapy (Frith, Harcourt, & Fussell, 2007; Luoma & Hakamies-Blomqvist, 2004). The response to treatment is individualistic; and while some side effects are common, their frequency and severity vary considerably (Macquart-Moulin et al., 1997). To understand this subjective experience of treatment, the present study interviewed women to explore and identify the coping strategies used to deal with the side effects of chemotherapy.

Despite its noted importance in determining distress (Hulbert-Williams et al., 2011), very few studies have examined coping appraisal within the context of the Self-Regulatory model. This may be due to a paucity of validated psychometric measures of assessment, as well as the inherent difficulties in measuring coping efficacy in cross-sectional studies. Coping appraisal was not examined in Study 2, but the appraisal of coping towards breast cancer treatment would be an important step towards understanding how it can influence coping and distress. In light of this, the current study qualitatively assessed coping appraisal in women receiving chemotherapy as part of treatment for breast cancer, and examined what women found effective in dealing with chemotherapy, not just what types of coping strategies were being utilised.

**Aim:** The aim of the current study is to examine how women with breast cancer cope with the side effects of chemotherapy.
Method

Participants

The sample consisted of 20 women living in Ireland who received chemotherapy as part of treatment for primary breast cancer in University Hospital, Galway between September 2007 and May 2011. Women were eligible to take part if they had a confirmed diagnosis of breast cancer, had completed chemotherapy as part of their treatment for breast cancer, were aged 18 years or over, and able to read and write English.

Procedure

Ethical approval was received from the Research Ethics Committees of the National University of Ireland, Galway, and University Hospital, Galway. Women were invited to take part in a qualitative study focusing on treatment for breast cancer. Information about the study, along with contact details of the researcher, was sent to women who had taken part in both time points in Study 2. In addition, women identified by the breast care nurses within the Symptomatic Breast Services, University Hospital, Galway, as eligible to take part were invited to participate. Women who agreed to participate and returned the consent forms to the researcher were contacted via phone, and a time was arranged to conduct the interview.

All interviews were conducted in person by the author and took place at the convenience of the participants, either within their home or in a public location such as a meeting room within the university. For each interview, participants were asked to describe their treatment for breast cancer. Specifically, each participant was asked to identify ways in which they dealt with chemotherapy. Average length of the interviews was 69 minutes 14 seconds ($SD = 32$ min 58 sec). The interviews were audio-recorded and transcribed using Express Scribe software into MSWord, before being transferred into QSR NVIVO10 software for analysis.

A total of 50 women were invited to take part. Three women declined to participate, and 3 women were too ill to be interviewed. No response was received from 17 women, so 27 were women eligible to take part.
Previous research has concluded that sample sizes of up to 12-15 are adequate for qualitative studies (Francis et al., 2010; Guest, Bunce, & Johnson, 2006), and the majority of qualitative studies include 10-20 participants. For these reasons, a sample of at least 15 participants was sought; with the final sample size determined based on the principles of saturation. After the 17th interview, a consistent pattern of responses was established across the interviews, indicating saturation had been achieved. Data collection was therefore discontinued after the 20th interview.

Measures and Materials

Interview schedule

The researcher conducted in-depth, semi-structured interviews that asked women to tell the story of how their diagnosis of breast cancer was made, the type of treatment received, and their experience of chemotherapy. In particular, the following questions, adapted from Lev and Owen (2000), were asked as probes to ensure that all factors were addressed: What kind of things did you do to deal with the side effects of chemotherapy? What was the worst part of the experience of chemotherapy? What was the best part of the experience of chemotherapy? What advice would you give to other women about to have chemotherapy? (Appendix I). Although these questions were available, most women readily told their stories, which included this information. Demographic information was collected from each participant before each interview, as well as medical information regarding type of treatment and surgery.
Results

Data Analysis

The interviews were coded thematically by the author. The thematic codes were designed to identify the main ways in which women coped with chemotherapy treatment. Results were organised by theme and subcategory, and quotes describing the themes were extracted.

Thematic analysis was used, following the guidelines set out by Braun and Clarke (2006). Firstly, the interviews were transcribed, read, and reread, in order to get an overall sense of each woman’s story. The researcher’s reflective notes were used to supplement each transcript. The first eight interview transcripts were analysed to identify themes in each transcript, and themes common to all eight transcripts. Each line of each transcript was analysed and coded openly. These open codes were then assessed for commonalities, and codes that had similar meanings were linked together to form a theme. Themes were then compared to one another, and sub-themes were established. This set of themes was then used to code the final 12 interview transcripts. Although the set of themes were used as a guide to code these transcripts, additional themes emerged during open coding, so the original coding framework was amended to incorporate these new codes. Once all transcripts were coded, the themes were again assessed for commonalities and distinctions and refined until a clear set of themes emerged. Illustrative quotations were compiled to give detailed descriptions of each theme (see Appendix K).

Sample Characteristics

The mean age of participants was 53.60 years ($SD = 7.74$, range = 38-65 years). All respondents were Anglo-Saxon in their cultural background. As can be seen in Table 27, seventeen women were married, while the remaining three women were single, separated, or widowed. Eighteen of the 20 women had children. Ten women received their treatment through the Symptomatic Breast Services in University Hospital, Galway, whilst the remaining ten women received their treatment through BreastCheck clinics, University Hospital Galway.
Fourteen women had breast conserving surgery, whilst four women had a mastectomy. A further two women had both breast conserving surgery, and a subsequent mastectomy. Eight women required further surgical procedures to remove tumours that had spread to lymphatic tissue (axillary clearance). Sixteen women received radiotherapy, and seventeen women were currently receiving hormone treatment. Eleven women received 4 sessions of chemotherapy, whilst the remaining nine women received 8 sessions of chemotherapy. One woman received a further 4 sessions of chemotherapy for brain metastases. The average length of time since diagnosis was 20.45 months ($SD = 11.49$, range = 9-48 months).
### Table 27.

*Summary of Demographic and Medical Variables of Women Interviewed*

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<th>Participant</th>
<th>Age</th>
<th>Marital status</th>
<th>Employment</th>
<th>Children</th>
<th>Location</th>
<th>Surgery</th>
<th>Radiotherapy</th>
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<td>Yes</td>
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<tr>
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<td>Yes</td>
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<tr>
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<td>Lumpectomy and axillary clearance</td>
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*Note. SBS = Symptomatic Breast Services*
Themes

Women engaged in numerous types of coping strategies to deal with chemotherapy. The three main sub-themes within coping include *behavioural coping*, *emotional coping*, and *coping appraisal*. A graphical illustration of these themes can be seen in Figure 3.

*Figure 3.* Graphical illustration of themes and sub-themes of coping with chemotherapy.
Behavioural Coping

Women engaged in a number of coping strategies that involved behavioural changes or maintenance of behaviour, with the emphasis on controlling the side effects and treatment. This theme was further classified into anticipatory coping, self-care behaviours, seeking information, and maintenance of activities.

Anticipatory coping

Based on the information available, a number of women engaged in anticipatory coping for dealing with some of the side effects of treatment. Specifically, anticipatory coping included preparing meals in advance, and preparing for hair loss. A third of the women had prepared meals in advance to cope with their inability to cook during treatment: Before I started the chemo, I had in the freezer ready meals ready, so I could just take one out for me. I also had meals ready for my husband and son who were living in the house, to take out (P8). This was especially important for women who were responsible for taking care of their families. This preparation helped women feel more in control and assuage their worry for how their families would cope during treatment.

All twenty women considered their hair loss as traumatic, and to reduce the distress of losing one’s hair, had prepared for hair loss by buying a wig. Although four women admitted that they believed they would not lose their hair, all women bought a wig in preparation. This was seen to be a way to avoid distress related to body image and loss of femininity, as well as a way to hide their illness and its effects from others.

Other anticipatory coping strategies utilised by women to deal with hair loss was to cut their hair shorter in the weeks leading up to the commencement of chemotherapy. This can be considered a form of behavioural rehearsal (Zannini et al., 2012), whereby women prepare for a change in appearance, and eventual hair loss by ‘rehearsing’ the event. Four women shaved their heads before commencing treatment, in an attempt to exert complete control over when they lost their hair, rather than waiting for it to fall out: I got rid of my hair before the cancer does. I had that control. I wanted that control, to control when it started … You went into chemo
feeling in control (P10). This sense of control was seen to be far more important in alleviating distress than preparing for hair loss.

Preparation for hair loss was not only employed to deal with women’s distress, but also to prepare others for change in their appearance. One woman asked her son to help her shave her hair, so that the novelty would combat the distress it may otherwise produce. Two women included their children in the process of choosing their wig to minimise the distress of seeing them without hair: They all came with me, they all went down one day, and we arranged to collect the wig. And they all picked a colour to put through. One picked a blonde-y colour and another picked another, so I was highlighted. So mom had her wig (P2). Women who engaged in anticipatory coping felt much better prepared, and experienced greater perceived control over treatment. Anticipatory coping was considered an effective way to combat feelings of self-consciousness and to alleviate worry about how it would affect the entire family.

Seeking information

Although all women reported receiving information about chemotherapy, the information provided was not specific enough to address individual concerns. One woman felt very unprepared and distressed prior to her first chemotherapy session, and mistakenly thought that treatment would cause her to vomit immediately: I was pure worried I was going to sick all over the place. I was like, (pause), terrified and I had to get half a valium to calm me down (P1). To avoid this distress, and to increase knowledge about how to deal with the side effects, twelve women actively sought further information about their treatment. Seeking information was considered to be important in determining the causes of cancer and understanding their treatment better. Women who sought information and felt that they held a strong understanding of their disease reported less distress when receiving treatment.

Written information was not considered to be useful, with many women reporting increased distress when reading information both in the form of leaflets and on the internet. The amount of information provided was often considered to be too detailed, and only focused on the medical aspects of treatment. Women felt that they did not receive enough information about how to deal with the side effects of treatment, leaving five women to feel overwhelmed, rather than reassured and
informed. Many women made the decision to avoid all forms of written information for the rest of their treatment after reading very distressing information: I gave my laptop away to my son, because I went on the internet before the chemotherapy and the first study (I saw) in breast cancer (told of) the different types of chemotherapy and how it can affect you and everything else. I wish I hadn’t (seen it) (P19).

Twelve women found it useful to obtain information by talking to others who had similar experiences. This was not only a source of information, but also a form of social support, whereby women could learn that they were not alone and that their experience was typical: I got a whole load of different bits of advice from different people, and I suppose that’s what is most useful. To let people know what to expect and also to give them helpful hints along the way really (P18). The ability to talk to similar others was considered valuable, both as a way to reduce distress, as well as a way to increase perceived control.

**Self-care behaviour**

Engaging in self-care behaviours was seen to be an important part of dealing with chemotherapy. Although most change in dietary behaviour was as a result of changes in taste and nausea from the chemotherapy, it was considered important to eat healthily as much as possible to avoid further side effects of the treatment: Nutrition as well is kind of important, when you’re going through chemo. Just to give you a bit of strength as well (P5); I made sure I ate, and I made sure that I ate something healthy at those times (P8). Drinking plenty of fluids was also seen as important for minimising the adverse effects of the chemotherapy, as well as helping women feel better.

Exercise was also seen as important to take control of one’s body and be able to influence recovery. One woman felt that she needed to join the gym during treatment, to ensure that she was giving herself the best chance of survival and of combating side effects such as fatigue: I used to go to the gym as well. It was doing harmless stuff but at least I felt I was trying to take control a little bit (P18).

Medication use was described by women as part of the process of dealing with side effects. Women took medication for specific side effects, such as anti-nausea medication, as well as medication for digestive symptoms. It was considered to be very important to take medication as prescribed, both to avoid and alleviate
side effects, as well as to enhance perceptions of active participation in the recovery process. One woman was conscious of the difficulties of adhering to the medication, whilst also being aware of its importance: *There was a lot of medication to take I suppose, between antibiotics and stuff ok. It was nearly a full time job trying to regulate it all, you know? . . . (but) take the meds as they’re prescribed, as I’d say some people try to be brave and don’t want to take them, you know. Take them, whatever gets you through* (P4).

Although a small number of women reported that engaging in self-care behaviours may not have directly influenced their recovery, the engagement of these strategies was considered important in establishing a sense of control over treatment. Many women did not feel in control over their treatment or recovery, and found this very distressing: *Your life’s not your own on chemo* (P10). Self-care behaviours were under the direct control of women, unlike the experience of side effects, so was considered to be an important way to feel part of their treatment: *I think that was maybe part of it too, you felt that there was something that I could do* (P8).

**Maintenance of activities**

All twenty women made attempts to maintain their routine and everyday activities as a way to regain a sense of control. The impact that treatment had on their ability to engage in activities made it much more important for women to be able to maintain a sense of routine, whether it was to continue to cook for themselves, or to engage in small tasks like walking to a shop to buy a newspaper: *I was going out and you know; going out to the pub or wherever. Wherever I would normally go. I didn’t think I should lie down and let it get to me* (P20).

Hospital appointments overtook many women’s lives, so engaging in routine activities was a way to try and break through this new routine of hospital appointments, and regain a sense of control over ones calendar: *I got so many letters through the post. My calendar for that full month of May was hospital, hospital, hospital. Every week there was some hospital appointment* (P15). It was important for women that their diagnosis was not the focus of their lives and that engaging in normal, day-to-day activities was a way in which to prove they had some control: *And the fact that I’m still here when they come in for school, I’ll still do the homework with them, and just try to be normal with them you know* (P5).
The most common reason women noted for maintaining their normal routine was to protect their family, especially their children, as much as possible from the effects of the treatment. It was seen as immensely important for women to shield their children from how much the treatment had affected them. Although all women displayed some level of fighting spirit, women with children tended to report a stronger need to survive and make it through the side effects, so that they would be there for their children. This insistence on maintaining a routine also helped participants to feel in control and to aid in this sense of fighting the illness, rather than giving up: *I kind of kept things as normal for them as well you know, and kept the house running as normal as I possibly could* (P3). Three women with very young children commented that they were the reason they got up every day, and wondered if they would have fought so hard without such an incentive.

**Emotional Coping**

Women also engaged in what can be termed emotional coping; coping strategies that aimed to reduce distress and minimise the psychosocial impact of treatment. These strategies included refocusing attention, reappraisal, emotional expression, and seeking support.

**Refocusing attention**

Refocusing attention was utilised to distract women from their treatment, and included reading, watching TV, or going on holidays. It was seen as a way to refocus ones attention on something more positive. Half of the women interviewed also planned positive and enjoyable activities during or after chemotherapy as a way to refocus attention from their diagnosis. Meeting friends for coffee during the days they felt better, or booking appointments for manicures or shopping were considered to be important forms of distraction from treatment: *If I was feeling good I’d go and have a facial, or I’d have reflexology* (P2); *go and get your nails done if you can’t go to the hairdressers, something like that* (P7). Planning enjoyable activities throughout treatment was also effective in helping women take time, and take care of themselves, rather than thinking about others.
Reappraisal

Reappraisal included attempts to view the situation and side effects of treatment in more neutral or more positive ways; for example treating hair loss as a good way to save money from hair dye and haircuts, and losing weight because of the inability to eat much due to nausea: *It’s the best diet you’ve ever been on! You lose a pile of weight first, and then the minute you get your taste back you’re stuffing your neck!* (P9). Humour was an important way to cope for one woman, who discussed how her ‘black humour’ helped her reappraise somewhat frightening aspects of her treatment as more positive. The use of reappraisal was seen to be an effective way of minimising the distress of the treatment and to perceive side effects as less noxious. One woman decided to reappraise the severe negative impact of her side effects as proof that the treatment was working: *My attitude at the time was well at least chemo is doing what it’s supposed to do … obviously he had given me the drugs, and they were doing what they were supposed to do* (P18).

Women also engaged in reappraisal by making downward comparisons to others with cancer so that their own experience was judged as less severe: *My best friend, she was actually worse than me with chemo. At least I didn’t collapse. She just couldn’t get out of the bed* (P10). Although these comparisons helped some women see their experience as less negative, they were not always effective. For example, one woman compared herself to others who were coping far better, which distressed her even more: *There were other people who were worse than me, and there were people who were getting the same treatment as me. Then there was an elderly lady who was getting the exact same treatment as me and she’d come over to me, say its better today and then hop off the bed, pick up her basket and off she’d go!* (P17).

Emotional expression

Emotional expression was used as a way to control emotions. Most women became very upset from their hair loss, and this was often the only time that women cried during the whole process: *When I went out into the car I cried and I cried and I cried* (P13). More than half of the women tried to keep their emotions in check so as not to upset their family and friends. In particular, many women discussed how they
tried to protect their families from becoming upset, and to do this, they kept their worries and distress to themselves: *I tried to keep a brave face to it all* (*P4*).

Not expressing emotions; however, often led to further problems with coping. For example, although the expression of emotions and distress was considered by some to be a normal part of the process, two women in particular found it difficult to do so. One woman noted how not crying in front of others made it more difficult for her to cope, as she did not receive as much support because it was assumed she did not require it. In hindsight, she reports that she would have received much more support had she expressed her distress more openly. Expressing emotions was considered to be a turning point for one woman in her ability to cope; once she allowed herself to express her distress, she was able to deal with the situation better: *I couldn’t lie down, so I baked a cake. In the middle of baking that cake, I just bawled my eyes out crying; I’d say for an hour. That got it out and I kind of coped then much better from then on* (*P17*).

**Seeking support**

Twelve women accessed cancer support services, and found them useful to varying degrees of success. The use of these services was seen to be a way of taking some time to oneself during treatment, without worrying about others: *I usually go in for mindfulness yoga for one hour. It’s lovely, you know just sit back and relax and close your eyes. It’s lovely* (*P16*). It was often noted that women felt uncomfortable expressing their concerns to family, so attending support services, whether it was attending a structured stress management programme, or simply talking to women who were also going through cancer treatment, was a way for women to express their fears and concerns without the need to protect others’ feelings. Talking to others with similar experiences also provided women with reassurance that their experience was typical, and provided a welcome source of information about coping with specific side effects: *Another thing that was really helpful was talking to other women who were going through it. That was really helpful. Because you weren’t trying to protect them, they knew what it was like* (*P8*). Moreover, discussing their experience of treatment with others was a way to normalise their own experience, reducing feelings of isolation and distress.
Women who did not talk to others about their experience found it much more difficult to cope. One woman in particular found it difficult to cope with her daughter’s reactions to her illness, and noted that support from other women would have helped her understand her daughter’s reactions more: *It would have been very helpful if I had someone who had been through it who had kids as well, and they had to deal with whatever issues that were thrown up with the kids. I could have thrown something like that against them and said is this normal like? Should their grades be falling, or should I be concerned when she’s locking herself in her room?* (P18).

### Coping Appraisal

Women also made appraisals about their coping, and discussed their perceived ability to cope with the side effects of chemotherapy, the difficulties they faced when attempting to implement coping strategies, and their perceived ability in their transition from ‘patient’ to ‘survivor’ once treatment was completed (Garofalo, et al., 2009).

### Coping ability

More than half of the women reported feeling able to cope with their diagnosis and treatment, with most perceiving that they coped well overall with chemotherapy: *I think I got more used to it and I was better able to pull yourself together* (P4); *I got through it very well and I got better than I expected* (P20). Perceived ability to cope was related to expectations of severity. For the most part, women either expected that the side effects they experienced would be less severe (*I was quite cocky about the whole thing really. This is doable, P11*), or more severe than they actually experienced: *I didn’t get any sickness. I was waiting for it to happen* (P15).

Coping with hair loss was generally considered a success. In particular, hiding hair loss was seen as successful, as family and friends often did not notice the difference between women’s hair and their wig. One woman found that her expectancies of losing her hair were more negative than the actual experience: *It was almost a kind of a novelty or whatever. I knew I was losing it so that was grand and I had got my wig, and I had got my headscarves and all that* (P5).
Experiencing more severe side effects than expected led to greater levels of distress and more negative impact, whilst believing that the side effects would be more severe led to an immense sense of relief when the experience was less noxious:  
*It wasn’t too bad at all. From what I saw; documentaries on the TV and that, I was pleasantly surprised; put it that way. It wasn’t pleasant but I was pleasantly surprised* (P20). One woman reported how she believed that chemotherapy would alter her forever, but was thankful to find that she felt like herself once treatment was completed:  
*I felt, whatever this is going to do to me to help me; the side effects, and the negative side; I am never going to recover from it. I actually felt that* (P12).

**Difficulties in coping**

All women reported some difficulties in coping with chemotherapy. Difficulties generally focused around coping such as engaging in self-care behaviours, and coping with hair loss. Although women engaged in anticipatory coping, they found that it was not always successful. For example, some women found it difficult to regulate their medication use, especially in terms of side effects such as diarrhoea and constipation:  
*The thing about those drugs are, they all constipate the bowel. Then if you have to get help with the bowel, you usually ended up taking a temperature because you got dehydrated with the bowel movements* (P10). For some, chemotherapy prevented normal dietary behaviours, which negatively impacted upon the preparations they made for when they were unable to cook:  
*I found with the chemo, my tastes changed. I couldn’t eat anything I’d prepared. I got cravings for things then that I didn’t have you know. So it didn’t work out so handy as I had prepared* (P8).

The most common difficulty in coping experienced, was coping with hair loss. All twenty women reported some problems with their wig; some were more minor issues such as it being too warm or itchy to wear. Some women felt so uncomfortable with their wigs that they were unable to wear them:  
*I had a wig and I wore it from here to a park that’s down there, back up again, and never again. It was the most horrible thing ever. I hated it.* (P14).

These problems with coping led to greater distress and further attempts to cope. Women wore bandanas and scarves instead of a wig, or asked family members to prepare meals for the rest of the family when they were unable. Medication use
was re-assessed and modified by healthcare staff to deal with the continued experience of side effects. Although these difficulties were seen to be distressing, they were also dealt with successfully for most women. For three women; however, the experience was so difficult that they felt at times they were not able to carry on:

_The thought at that moment of having 4 (sessions of chemotherapy); I can’t say I would have wanted to kill myself, but I would be close. I just, at that point I thought I couldn’t handle that_ (P12).

**Transitional coping**

The majority of women found it difficult to make the transition from ‘patient’ to ‘survivor’ (Garofalo et al., 2009). Medical appointments and treatment had become the new routine for women, and the removal of that left many feeling unsure what to do once treatment was completed: _I am at a loss, because it was like a job. At the same time things were happening at the same time every day for five days a week. Now it’s what do I do? (P15); it had become such a part of my day, I was like really? What am I going to do now? (P6)._ This change from constant medical appointments to limited follow-up care was a source of distress in some women, as reassurance of care was removed, leaving them feeling exposed and vulnerable: _Having been so dependent on them, suddenly thinking how am I going to survive without them? (P18)._

One woman in particular was very concerned about recurrence, and saw the removal of care a sign that a recurrence was inevitable. This woman was preoccupied by the possibility of a recurrence, which was heightened by her knowledge of her extensive family history of breast cancer. Moreover, her experience of chemotherapy was very distressing; she was fearful of needing chemotherapy again in the future: _I’m afraid, I’m anxious, and it’s probably what’s causing me broken sleep all the time, it’s that I am afraid. It’s a combination of being afraid that it’s going to turn to cancer, and being afraid that I’m going to have to do chemo again when it’s unavoidable_ (P10). She believed prophylactic mastectomy of her unaffected breast to be the only option to avoid chemotherapy, but was dissatisfied with healthcare staff who did not recommend the procedure.

Some women found the transition relatively easy; citing return to work as a way for them to regain a sense of normality. At the same time, five women were too
unwell to return to work due to the continued experience of side effects from chemotherapy after treatment ended. These women reported continued distress, and further worry and uncertainty about the future.
Discussion

The current study examined how women cope with the side effects of chemotherapy. Women utilised a wide range of coping strategies that served different functions. Behavioural coping was utilised to gain a greater sense of control over the disease and associated symptoms and recovery, whilst emotional coping was used to minimise the emotional distress and anxiety experienced as a result of treatment. Previous researchers have indicated that effective strategies to reduce anxiety in chronic illness overlap with the coping strategies reported in the current study (Cameron & Jago, 2008; Gross, 1999). These include attention deployment, proactive behaviours, and cognitive change through reappraisal. Previous research asserts that differing coping strategies are more adaptive for certain situations (Carver et al., 1993; Endler, Kocovski, & Macrodimitris, 2001; Stanton & Snider, 1993), and that a combination of coping strategies is used to cope with chemotherapy (Bussell & Naus, 2010; Shapiro et al., 1997). Both forms of coping were used by women in the current study, so it may be that a combination of coping strategies is important during chemotherapy, rather than just problem-focused coping.

Behavioural coping was used to cope with the specific consequences of chemotherapy. Specifically, anticipatory coping such as buying a wig was used to counteract increased feelings of self-consciousness and to combat feelings of loss of control. Frith, Harcourt, and Fussell (2007) also provided evidence that women engage in anticipatory coping for hair loss, as a way to become ready and accept the side effects of treatment. Similarly, advance planning has been reported to deal with other side effects such as fatigue (Magnusson et al., 1999). Anticipating side effects and engaging in strategies to minimise their impact highlights the importance of the provision of accurate information of the side effects of treatment, and the potential for anticipatory coping as an effective intervention to reduce distress in women receiving chemotherapy.

Written information was considered inadequate and unwelcome. This was often related to its lack of specificity, and the provision of too much detailed but irrelevant information. Previous research has shown that providing detailed information that is not specific to the individual can be distressing, and lead to a reluctance to receive treatment (Kreling, Figueiredo, Sheppard, & Mandelblatt,
Women prefer to receive information that is tailored to them, and that addresses their specific information needs (Brown, Koch, & Webb, 2000). Information on treatment and treatment-related side effects is frequently cited as the most important informational need of cancer patients (Mills & Sullivan, 1999; Morrison et al., 2012). In the current study, seeking information from similar others, was considered much more useful than medical information. McCaughan and Thompson (2000) discovered that almost half of their sample of cancer patients reported seeking information from others with cancer. According to Buunk and colleagues (2012), the use of information from other patients acts as a reference point, whereby patients can assess how their experience relates to others. The results suggest that the provision of specific information relating to how to effectively cope with the side effects, delivered by other patients, may be more useful than providing basic information in other forms.

Engaging in self-care behaviours and maintaining routine activities were also used to cope with side effects of chemotherapy. The importance of maintaining activities such as work and childcare have been seen previously as a way to regain a sense of control (Landmark & Wahl, 2002; Luoma & Hakamies-Blomqvist, 2004). Previous research has shown that women are more likely to maintain their normal activities during treatment if they hold high levels of self-efficacy (Henselmans et al., 2010). In confirmation of this, women reported engaging in routine activities as a way to counteract loss of control, as well as to actively participate in their recovery process. Moreover, women participated in their recovery by engaging in self-care behaviours such as good nutrition, exercise, and medication adherence.

Perceived control over behaviours and emotions were considered to be important in alleviating distress. Patients with early stage breast cancer need to feel a sense of control, even if these beliefs are not based on objective indices of disease (Taylor, 1983; Thompson et al., 1993). Most theories of adjustment to chronic illness include some form of perceived control or self-efficacy (Lev, Paul, & Owen, 1999), and both of these constructs have been implicated in distress in women with breast cancer (Cunningham, Lockwood, & Cunningham, 1991). The use of activity or behavioural-based coping is consistent with self-efficacy theory, in that women who report high levels of self-efficacy report less distress. Lev and Owen (2000) examined self-efficacy in 60 women receiving chemotherapy for breast cancer. Although coping was not directly assessed, the authors noted that women engaged in
cognitive strategies to reappraise the situation in more positive ways, maintaining support from others, and discussed the importance of control.

Emotional coping such as refocusing attention was employed to minimise distress that women experience as a result of treatment. The use of distraction techniques such as this have been highlighted previously as ways to combat emotional distress (Drageset, Lindstrøm, & Underlid, 2010; Luoma & Hakamies-Blomqvist, 2004). In addition, positive reappraisal has been indicated as a way to decrease distress (Karademas, Argyropoulou, & Karvelis, 2007; Sears, Stanton, & Danoff-Burg, 2003), but is often discussed in terms of reappraising the impact of a cancer diagnosis. The current study highlighted that women engage in very specific forms of reappraisal to minimise the psychological impact of treatment side effects. The use of reappraisal therefore can be an effective form of coping with both general and specific aspects of a disease.

Women considered emotional expression as adaptive, but many women were unwilling to express their emotions. This suppression of emotions was unhelpful and ineffective, leading to greater psychological distress. Greater use of emotional suppression has been shown to predict greater distress (Iwamitsu et al., 2005; Owen, et al., 2006). Stanton and colleagues (Stanton et al., 2002) reported that emotional disclosure is considered to be an effective form of intervention to increase emotional expression and reduce distress in women with breast cancer who report low levels of cancer-related avoidance, whilst expressing positive emotions in relation to breast cancer was effective in women with high levels of avoidance. Encouraging emotional expression and positive reappraisal may lead to reductions in distress in subgroups of women, providing evidence for the evaluation of both emotional expression and positive reappraisal as intervention components to reduce treatment-related distress.

Seeking support from other patients was utilised, and is often seen as an adaptive coping strategy to alleviate distress (Thuné-Boyle et al., 2012). Most women also reported engaging in downward comparisons with others, which are highlighted as a way to restore self-esteem and alleviate distress (Buunk et al., 2012; Taylor et al., 1984). Cancer support services are becoming more available, and the provision of support from similar others, as well as encouragement to engage in emotional expression, according to the current findings, will be beneficial. Despite this, few women in the current study utilised these services. Access to these services
was not available to some women due to their geographical location or financial status, whilst others were unaware of the services available to them. The provision of information about local and national support services, as well as better access to these services, is needed so that women can utilise these resources.

The results provide some evidence for the concepts of danger control and fear control. Danger control, according to the original Self-Regulatory model, is utilised to engage in specific behaviours in relation to external threats, whilst fear control includes responses aimed to minimise the distress associated with the threat. Chemotherapy provides an opportunity to engage in limited strategies to deal with side effects, whilst also increasing distress. The model suggests that danger control and fear control interact, and in confirmation of this, women engaged in strategies that included both behavioural and emotional responses to chemotherapy. These results highlight the Self-Regulatory model as a parallel-processing model, and its ability to explain responses to chemotherapy. The use of coping to maintain a sense of control is also related to the distinctions between behavioural and cognitive control proposed by Thompson and colleagues (Thompson et al., 1993). Behavioural control includes engaging in behaviours that can directly affect the negative impact of events such as chemotherapy. Cognitive control is the belief that one holds cognitive strategies that are effective in minimising the emotional impact of events (Thompson, 1981).

Confirming its importance in the Self-Regulatory model, coping appraisal was discussed by women as an important aspect of coping. Women who perceived that they were coping effectively with their side effects reported less treatment-related distress. In contrast, women who had difficulties implementing coping strategies felt more distressed, reported more problems in general, and attempted to cope using alternative strategies. Moreover, the expectancies of severity of symptoms further contributed to coping appraisal and distress. Women who expected fewer symptoms of treatment were more distressed, whilst women who expected more severe consequences reported high levels of anticipatory distress. The findings highlight how the inclusion of coping appraisal is important, despite its lack of measurement in other studies (Hulbert-Williams et al., 2011; Wang et al., 2004). Modifying appraisal of coping and coping strategies may be an effective means of reducing distress in this illness group.
Women reported some difficulties in coping with the end of treatment. Patients feel vulnerable to recurrence and feel less supported from healthcare staff due to limited follow-ups and check-ups once treatment has ceased (Thuné-Boyle et al., 2012). This was supported by Jones and colleagues (Jones et al., 2010) whereby women with breast cancer felt abandoned by healthcare staff once treatment was completed, and unprepared for the transition. When diagnosed, women will often require treatment that spans a year. During this time, women are supported by healthcare staff, so it is to be expected that women may experience some difficulties after treatment has ended and this support is no longer available (Garofalo et al., 2009). Further information about how women experience this transition may improve support services and effective communication from healthcare staff. The provision of this support may help women feel more prepared during this time, encouraging better transition after treatment.

Although women were not asked explicitly about illness perceptions, women often discussed their cognitions about breast cancer when talking about coping with chemotherapy. More research is warranted to determine their influence on disease and their effects on distress during treatment. Despite this, the current study provides some indication of how perceived control can relate to both coping and distress in women receiving chemotherapy.

**Implications**

These results have implications for future research aimed at developing more realistic expectations of treatment in women with breast cancer. This is one of the first studies to examine specific coping strategies used when dealing with chemotherapy, and the findings can inform future studies that aim to increase control through the encouragement of specific types of coping. Interventions that focus on establishing high levels of control and autonomy through coping may decrease distress. Burish, Snyder, and Jenkins (1991) compared relaxation training and coping skills in 60 cancer patients receiving chemotherapy. The coping skills training group reported reductions in depression, as well as reductions in side effects such vomiting and anticipatory nausea. The current findings suggest that interventions that can foster a sense of control by encouraging coping strategies to deal with the side effects of chemotherapy, may lead to reductions in distress during treatment.
Although these findings are encouraging, more research is needed to test this assertion.

Developing self-efficacy beliefs may be an important component of interventions (Lev, Paul, & Owen, 1999). The use of social cognitive theory components such as performance accomplishments, vicarious experience, verbal persuasion and physiological arousal may help to increase self-efficacy and more effective coping (Bandura, 1977). Studies that include coping appraisal may highlight why some women continue to experience distress, despite engaging in coping to minimise their distress. Additionally, to improve coping after completion of treatment, research should focus on developing clear communication and presentation formats for communication between patients and healthcare staff. These interventions can utilise the Self-Regulatory model as a guide, which can ultimately lead to better functioning and less distress in women with breast cancer.

Limitations

The interviews were retrospective, which can be problematic in relation to accuracy of recall. Women were interviewed an average of twenty months after diagnosis, which was roughly eight months after chemotherapy was completed. Time-series designs may be more useful in this context, in that women may be interviewed at multiple time points to assess their coping and coping appraisal throughout treatment. This is time and resource-intensive however, so the current study provides a basis for future research.

Women were sampled from one of the eight cancer treatment centres in Ireland; this treatment centre provides service to a large geographical area. Despite this, the inclusion of only one treatment centre may limit the generalisability of the results to all women in Ireland.

Conclusions

This is one of the few studies that have examined coping in women during chemotherapy, and is the first to examine coping appraisal, an important component of the Self-Regulatory model. Women engage in specific coping strategies to deal with the side effects of treatment, in an attempt to control the physical impact of
Chapter 5: Study 3

des these treatment effects, as well as their emotional response. The results highlight the importance of specific coping strategies and coping appraisal as determinants of distress, and the findings have direct applications to the development of interventions to enhance a sense of control and reduce distress through encouraging adaptive coping in women with breast cancer who are receiving chemotherapy.
CHAPTER 6: GENERAL DISCUSSION

Overview of Findings

This research examined the factors influencing distress in women with breast cancer. The research aimed to a) assess how risk and illness perceptions predict worry in healthy women from the community; b) assess how experience of breast cancer predicts differences in illness perceptions and breast cancer worry; c) assess how illness perceptions and coping predict distress in women with breast cancer; and d) assess how women cope with chemotherapy for breast cancer.

The research utilised a mixed-methods design to assess distress in women with breast cancer within the theoretical framework of the SRM. Yardley and Bishop (2008) assert that the use of both quantitative and qualitative methods provides a better insight into research questions, and allows further exploration that may not be possible when only one approach is used. The use of both methods allows for the collection of different levels of knowledge, providing a wider picture of a situation or phenomenon (Pope & Mays, 1995). In the context of the current research, Study 3 allowed for a more detailed examination of the relationship between coping and distress, which was not possible in the quantitative studies. These results complemented the quantitative findings from Study 2, which indicated that coping was a predictor of cancer-related distress over time. In addition, the combination of this series of studies allowed for a greater understanding of the interaction between illness perceptions, coping, and coping appraisal within the SRM.

Study 1

In Study 1a), a large group of healthy women in the community completed measures of risk and illness perceptions of breast cancer, to assess whether they predicted levels of breast cancer worry, and breast cancer screening intentions. Women who held high levels of perceived risk, stronger illness coherence, more negative emotional representations, and more chronic timeline beliefs reported greater worry. Risk perceptions partially mediated the relationship between illness perceptions and breast cancer worry, and also partially mediated the relationship
Chapter 6: Discussion

between optimism and breast cancer worry. Risk and illness perceptions did not explain a significant amount of the variance in intentions to attend breast cancer screening or breast self-examination. The findings also demonstrated that the type of measurement of risk perceptions that was used determined the estimated risk of developing breast cancer in the future. The use of verbal and comparative scales led to more optimistic estimates, whereas numerical scales led to more pessimistic risk estimates. The study provided evidence that risk and illness perceptions are related, indicating that the Self-Regulatory model could be expanded to include measures of risk, and may help to increase the predictive value of the model in healthy populations.

Study 1b) distinguished between 99 healthy women who did and did not have a family history of breast cancer, and compared their perceptions and distress with 60 women who had been diagnosed with breast cancer 12 months previously. Women with breast cancer reported more acute timeline beliefs and more severe consequence beliefs than healthy women, regardless of family history. Healthy women with no family history reported higher external causal beliefs of breast cancer. Healthy women with a family history of breast cancer reported the lowest levels of breast cancer worry. In sum, the study has contributed to the small but growing literature that family history and personal experience of breast cancer can impact upon illness perceptions and disease-related distress.

Study 2

In Study 2, women diagnosed with breast cancer completed measures of illness perceptions and coping, to determine their influence on distress at diagnosis, and 12 months post-diagnosis. At diagnosis, illness perceptions were more predictive of distress than coping. Holding a strong level of personal control predicted greater levels of depression, whilst strong illness coherence beliefs and less behavioural causes predicted less cancer-related distress. In contrast, illness perceptions did not predict any of the variance in distress 12 months post-diagnosis. Coping predicted a modest amount of the variance in cancer-related distress at diagnosis and 12 months post-diagnosis. The use of anxious preoccupation as a coping strategy mediated the relationship between illness perceptions and distress. Overall, the findings
demonstrated that both illness perceptions and coping strategies play a role in determining distress in women with breast cancer.

**Study 3**

Building upon the finding that coping was a predictor of distress, women who received chemotherapy as treatment for breast cancer were interviewed in Study 3 to examine how they coped with the side effects of treatment. Women engaged in very specific coping strategies to deal with the side effects of chemotherapy. In particular, women engaged in behavioural strategies such as seeking information and self-care behaviours to gain a sense of control over their symptoms; whilst they engaged in emotional coping to deal directly with treatment-related distress. Women’s appraisal of the efficacy of the coping strategies they employed also had a direct influence on distress. Women who had negative expectancies about coping effectively reported more anticipatory distress, whilst women who reported problems implementing coping strategies reported greater distress during treatment. The study highlighted the types of coping strategies women employ to deal with the side effects of treatment for breast cancer, and how these findings can be incorporated with the quantitative results from Study 2. Moreover, the study provides insight as to how coping and coping appraisal may interact within the context of the SRM. The findings also provide important information for future interventions aimed to reduce distress in women receiving chemotherapy.

**Overall Implications**

**Risk and illness perceptions and the Self-Regulatory Model**

Risk perceptions and illness perceptions were important determinants of breast cancer worry, but not of screening intentions. Very few studies have assessed risk and illness perceptions together (Kaptein et al., 2007; Rees et al., 2004), but the current findings suggest that more work is warranted to assess how these constructs interact with one another. The SRM is a useful model, and its applicability to healthy populations is becoming more pertinent with the advent of screening programmes for cancer, and the availability of genetic susceptibility testing for breast cancer and other illnesses. Also of relevance is that illness perceptions are developed from a
variety of sources, so they may be fully developed before individuals are diagnosed with an illness. Measurement of illness perceptions in at-risk or healthy populations may be an avenue of future research that may explain both an individuals’ response to a diagnosis, as well as to the perceived risk of developing a disease. It emerged that the type of measurement of risk determined the level of reported optimism or pessimism. There is no standardised measurement of risk perceptions, so the current research provides a unique insight into how risk perceptions can vary based on the method of measurement, and emphasises the value of measuring risk perceptions in a variety of ways.

Illness perceptions and coping in breast cancer

Women with varying experience of breast cancer, based on their family history and a personal diagnosis of the disease, held different perceptions of breast cancer. In Study 1a), women without a family history of breast cancer reported lower illness coherence beliefs in comparison to women with a family history. In Study 1b), these relationships did not reach significance, but showed a trend in the same direction. Chronic timeline beliefs were lower in women with breast cancer, whilst healthy women without a family history reported the most chronic timeline beliefs. Likewise, consequence beliefs were higher in women with breast cancer, than in healthy women with and without a family history. The findings suggest that illness perceptions may be fully developed before individuals are diagnosed with an illness. These perceptions may relate to behaviours such as screening, as well as responses to a subsequent diagnosis of breast cancer, so further research is needed to shed more light on this.

Illness coherence was reported to be an important predictor in the current series of studies. In Study 1a), greater perceived coherence over breast cancer led to increased breast cancer worry in healthy women; whilst in Study 2, women with breast cancer who reported higher coherence beliefs reported less cancer-related distress. Illness coherence thus has an important role in determining distress in relation to breast cancer. Previous research has indicated that illness coherence is predictive of better functioning in patients with cystic fibrosis (Sawicki et al., 2011), and less depression in cardiac patients (Juergens et al., 2010). Findings in the current study suggest that believing that one understands breast cancer is a protective factor.
for distress when diagnosed with the disease, but is a predictor of more distress in healthy women with a family history of breast cancer.

Previous research has suggested that information provision is associated with illness coherence and distress. Husson and colleagues (Husson et al., 2012) examined illness perceptions and information provision in 3080 cancer patients. The provision of accurate, disease-specific information was associated with greater illness coherence, whilst general medical information was associated with lower illness coherence beliefs. Higher satisfaction with information provided was also related to higher coherence beliefs (Husson et al., 2012). The provision of specific disease information was considered to be an important form of behavioural coping in Study 3, further suggesting that the provision of disease-specific information to women with cancer may reduce distress by improving illness coherence.

High levels of illness coherence in women with a family history may be related to their knowledge of breast cancer. Women with a family history of breast cancer may have acquired their knowledge of the disease through affected family members. Although this knowledge may lead women to believe they have a stronger understanding of the disease, if the experience of breast cancer was negative, this knowledge may be overwhelming, and lead to increased distress. The mechanism of how illness coherence predicts breast cancer worry in healthy women is speculative; further work is needed to assess the level of direct exposure to women with breast cancer, and whether this experience was positive or negative, as well as to assess the accuracy of breast cancer knowledge.

Although illness perceptions such as illness coherence were predictive of cancer-related distress, other illness perceptions have a more indirect effect on distress. The influence of chronic timeline on breast cancer worry in Study 1a) was partially mediated by risk perceptions, and in Study 2, the influence of cyclical timeline on cancer-related distress was fully mediated by greater anxious preoccupation. Consequence beliefs did not directly influence levels of distress, but its influence on cancer-related distress in women with breast cancer was also fully mediated by anxious preoccupation. In addition, the influence of illness coherence on cancer-related distress and general anxiety in Study 2 was mediated by anxious preoccupation. The impact of illness perceptions to worry and distress is at least partially mediated by risk perceptions and coping. This may account for the diverse levels of variance in distress accounted for by illness perceptions in previous studies.
Chapter 6: Discussion

(Dorrian et al., 2009; Frosthom et al., 2007; Millar et al., 2005). The development of more longitudinal studies that include perceptions of risk and coping can help to clarify how illness perceptions exert their influence on distress, but the current research suggests that some illness perceptions may have a more indirect influence than previously assumed. Few studies have found coping to be a mediator of illness perceptions and distress previously (Gould et al., 2010; Rutter & Rutter, 2002), so the results reflect the complexities of the relationships in the model, and underscore the importance of including measures of coping when examining illness perceptions and distress.

The importance of perceived control is highlighted in social learning theories (Bandura, 1977; Rotter, 1966), learned helplessness (Seligman, 1975), cognitive adaptation models (Taylor, 1983), as well as in the Self-Regulatory model. In this way, many studies report high levels of perceived control to be associated with less distress and depression (McCorry et al., 2012; Millar et al., 2005; Sawicki, et al., 2011). In contrast to previous research, Study 2 indicated that women who held high levels of personal control over their breast cancer reported more depression at diagnosis. There is some suggestion that although perceived control is beneficial in most situations, perceived control over an uncontrollable situation, such as the development of cancer, is not adaptive, and will lead to more distress (Newsom et al., 1996; Schiaffino, Shawaryn & Blum, 1998; Tomich & Helgeson, 2004). Most theories of adjustment include some aspect of the concept of control (Lev, Paul, & Owen, 1999), so it is important to be aware of both the importance of control in determining distress and adjustment, as well as the potential disparities in how control is measured. The ability to make comparisons across studies is limited by the variety of ways in which control has been assessed (Carver et al., 2000). Control within the IPQ-R distinguishes between personal and treatment control, so perhaps it is necessary to further define these constructs; for example, distinguishing between personal control over the disease, or personal control over side effects of treatment.

In Study 2, coping was seen as a predictor of cancer-related distress at diagnosis and 12 months post-diagnosis, but the variance explained was small. This may have stemmed from the fact that overall coping of the diagnosis of breast cancer was assessed, rather than more specific coping towards specific challenges of the disease. Study 3 addressed this issue by examining coping with chemotherapy. Findings indicated that women engaged in a number of strategies to cope with the
side effects of chemotherapy. Women engaged in behavioural and emotional coping to minimise the impact of side effects, and maintain a sense of control over the situation. This is in line with previous research that suggests that women engage in different coping strategies according to the demands of the situation (Carver et al., 1993; Stanton, Danoff-Burg, & Huggins, 2002). In addition, coping appraisal influenced both distress and further coping efforts, highlighting its importance in determining distress (Hulbert-Williams et al., 2011; Wang et al., 2004).

Although women were not asked explicitly about illness perceptions, women often discussed their perceptions about breast cancer. Specifically, women discussed how their coping was motivated to gain and maintain a sense of control. Engaging in coping strategies to develop a sense of both behavioural and cognitive control has been suggested previously (Thompson, 1981). These findings indicate that perceptions such as control are important in determining coping strategies in women with breast cancer, and that these combine to influence levels of distress. These results, along with those from the quantitative studies, provide evidence for the cyclical nature of the SRM, by illustrating that women engage in coping to influence their perceptions; namely perceived control. More research is warranted to determine the influence of illness perceptions on disease and their effects on distress during treatment, but taken together; the studies form a clearer picture of how these variables determine distress in breast cancer.

The findings from these earlier studies, as well as the current research, suggest that control over specific challenges such as side effects of treatment may be more adaptive than perceived control over the illness itself. In this way, interventions to modify control may be effective in reducing distress and increasing adaptive coping (Lev & Owen, 2000). Previous research has conducted interventions that modify illness perceptions in patients with MI (Broadbent, Ellis, Thomas, Gamble, & Petrie; 2009; Petrie, Cameron, Ellis, Buick, & Weinman, 2002). Only one study to date has attempted to measure changes in illness perceptions and distress as part of an intervention in women with breast cancer (Lichtenstein Jørgensen et al., 2009), but the authors did not report any changes in illness perceptions or distress. Further work is needed to establish an intervention, as well as to adequately test its ability to influence distress and illness perceptions.

Although promising, the variance explained by illness perceptions in Study 2 was moderate at diagnosis, but did not predict any of the variance at 12 months post-
diagnosis. Although the variance explained by coping on distress was small in Study 2, anxious preoccupation was a predictor of cancer-related distress at diagnosis and at 12 months post-diagnosis. From this, interventions aimed at time of diagnosis may more usefully focus on modifying illness perceptions, but interventions that target women during or after their treatment may benefit more if focused on coping and coping appraisal. Illness perceptions are relatively stable over time in women with breast cancer (McCorry et al., 2012). In contrast, coping is more dependent on the specific stressors or challenges faced (Boyes et al., 2009), suggesting that coping may be more amenable to change than illness perceptions. In addition, the modification of coping may elicit changes in illness perceptions (Lichtenstein Jørgensen et al., 2009; Petrie et al., 2002). The use of interventions to encourage more proactive coping to deal with the side effects of chemotherapy, as well emotional coping such as the encouragement of emotional expression and reduction in anxious preoccupation, may be beneficial.

Although the current research indicates that the Self-Regulatory model may be influential in determining distress in relation to breast cancer, the model has some limitations. Since the development of measures such as the IPQ and IPQ-R, the vast majority of research has focused solely on illness perceptions, and has not consistently included coping or coping appraisal. This has led to an inability to adequately test the entire model in a single study. At the same time, there are some limitations to using these illness perception measures. For example, in the present study, internal reliabilities for some of the subscales were appropriate, whilst others did not reach the satisfactory level, indicating that these variables may not have been as appropriate or relevant to the current population.

The inclusion of emotional representations as a subscale in the IPQ-R may be conceptually similar to adjustment and distress. This was addressed in the current research by assessing the relationship between these variables, and in some cases excluding it from the analyses. Despite this, the use of this subscale in other studies may indicate that the measure as a whole may not be as appropriate for all conditions and populations. Similarly, factor analyses are required to distinguish between causal attributions in the measure, but the sample size required to conduct these analyses are often very difficult to obtain in clinical populations such as in women with breast cancer. Although the measures are useful and have been validated across a number
of conditions and populations, the development of other methods to elicit illness perceptions may be more useful and appropriate in the future.

**Recommendations for Future Research**

Overall, the results of this research suggest that illness perceptions, coping and coping appraisal are important aspects of the SRM. The Self-Regulatory model is a cyclical model, so future work should measure these constructs in the same sample. Moreover, their measurement at diagnosis, during treatment, and after completion of treatment will provide a clearer understanding of the impact of these components to distress in women with breast cancer over time. Future research in women receiving chemotherapy could also include multiple interviews throughout treatment. Most qualitative research is conducted at one time point only; it may be more useful to assess coping and coping appraisal over multiple time points, to generate a richer, more detailed understanding of how women cope on a day-to-day basis. Very little research has assessed the utility of interviewing participants more than once, but Flowers (2008) suggests that it can be an effective way to determine changes over time, as well as a way to establish rapport and trust with participants, leading to more opportunities for disclosure.

The measurement of illness perceptions have been standardised through the use of measures such as the IPQ, IPQ-R and BIPQ, but recent developments have led to other, more novel ways to elicit illness perceptions. For example, drawings have been used to elicit illness perceptions in MI patients (Broadbent et al., 2004), as well as in women with breast cancer (Harrow et al., 2008). The use of this technique can be incorporated into interviews, allowing for greater elaboration of the illness perceptions that women hold of their cancer (Diefenbach & Leventhal, 1996). The use of graphic elicitations techniques such as these in qualitative research is becoming a popular method to generate meaningful discussions that may not be amenable to standard interviews (Bagnoli, 2009). Moreover, the elicitation of illness perceptions in this way can be used to assess changes over time, for example before or during chemotherapy, and may be more practical in some circumstances than administering lengthy measures such as the IPQ-R at each time point.

In the same way that drawings would be useful to elicit illness perceptions in future research, the use of the Assessment of Illness Risk Representations (AIRR;
Chapter 6: Discussion

Cameron, 2008), can be used to examine the relationship between illness and risk perceptions. Cameron (2008) has used this measure to elicit risk representations of skin cancer. Its expansion to assess perceived risk of breast cancer may help to provide further insight into how risk perceptions may influence behaviours and worry of developing the disease in the future.

The current research focused almost exclusively on the role of the SRM in predicting distress. Although it is important to assess how the model affects distress, further work can assess how the model influences behaviour such as adherence to screening recommendations. Illness perceptions have been implicated as predictors of health behaviours in patients with cancer (Christensen et al., 1999; Costanzo, et al., 2011), as well as mammography screening attendance in healthy women in the community (Lostao et al., 2001). Similar to other studies (e.g. Byrne, Walsh, & Murphy, 2005), in Study 1a), illness perceptions did not predict behaviours. Future research is required to examine the role of the SRM in predicting behaviours such screening in women with breast cancer.

Risk perceptions have been implicated as predictors of behaviours such as vaccination (Brewer et al., 2007), but very little research has explicitly measured their influence on breast cancer screening (Katapodi et al., 2004). Future research can expand upon the current findings by measuring adherence rates to screening and observable behaviours in healthy women. In addition, risk and illness perceptions, as well as screening behaviours, could be measured in women with or without a family history of breast cancer, so that their predictive influence can be examined.

In the current research, it was not possible to compare women diagnosed through this breast cancer screening programme, and women diagnosed through referral services with symptomatic disease. Few studies have assessed the differences in distress in women who received a diagnosis in screening or self-detection (Burgess et al., 2002; Kennedy et al., 2010), and no studies to date have assessed their perceptions of the disease. This is an important issue as the prevalence of screening programmes will increase incidence rates, leading to more women being diagnosed with breast cancer in this way. Research examining differences in distress and illness perceptions across these groups will be useful in the future, as this may have implications for response to treatment and overall adjustment.
**Future interventions: Preparing for chemotherapy**

Study 3 highlighted that some women find it difficult to make the transition from patient to survivor (Garofalo et al., 2009). Women have also reported feeling abandoned after treatment is completed (Jones et al., 2010; Thuné-Boyle et al., 2012), so there is a need for the provision of psychological support after completion of treatment. Interventions should ideally focus on helping women make this transition. The current research; however, provides some evidence for the utility of interventions that focus on improving perceived control, and encouraging adaptive coping in women receiving chemotherapy for breast cancer.

According to the Self-Regulatory model, effective interventions require the incorporation of strategies that patients can use to monitor themselves over the course of the illness and deal with the emotional and physical challenges that it brings (Buick & Petrie, 2002). Interventions that include self-regulation techniques such as relaxation, goal setting, coping skills, and positive reframing can provide patients with direction over their illness experience (Petrie et al., 2003).

Cameron and colleagues (Cameron, Booth, Schlatter, Ziginskas, & Harman, 2007) developed an intervention based upon an expanded version of the SRM to improve adjustment in women with breast cancer. The intervention was composed of coping strategies to improve emotional regulation. Higher control beliefs and higher perceived coping efficacy in the intervention group were reported up to 12 months later. This study is promising in that control beliefs were positively modified, but the sample had already completed treatment. Women find treatment such as chemotherapy distressing (Farrell et al., 2005), so the replication of this kind of intervention, specifically aimed at preparing women for chemotherapy, may be effective in reducing distress and increasing coping appraisal and control.

Cognitive-behavioural techniques have been shown to provide the best strategies for reducing side effects of treatment (Newell, Sanson-Fisher, & Savolainen, 2002), but no one intervention aimed at reducing distress has been identified as effective (Fawzy, 1999). Interventions that focus on developing coping strategies in women during chemotherapy to deal with side effects as well as to enhance control and reduce distress would be beneficial. One such intervention to prepare for chemotherapy can be developed directly from the current research findings. Attention deployment, proactive behaviours, cognitive change, and
response modulation, are considered to be important ways in which to alleviate illness-related anxiety (Cameron & Jago, 2008; Gross, 1999). These map on to the kinds of coping strategies women engaged in to cope with the side effects of chemotherapy in Study 3. For example, the encouragement of coping strategies that were considered effective in Study 3 may lead to more positive coping appraisal, reductions in distress, and increased feelings of control in women about to receive chemotherapy. Specifically, engaging in anticipatory coping and self-care behaviours may increase feelings of control; whilst refocusing attention, positive reappraisal and seeking social support from similar others can be encouraged to reduce distress.

The provision of disease and treatment-specific information is also considered important (Brown, Koch, & Webb, 2000), so information provision can be incorporated into such an intervention. Likewise, Study 3 highlighted the perceived value in receiving information from similar others, so the proposed intervention could build upon this, using principles of self-efficacy theory. Bandura (1977) posited that self-efficacy is determined by four sources of information; performance accomplishments, vicarious experience, verbal persuasion, and physiological arousal. The use of similar others to provide information can be provided as a form of vicarious experience; women learn to cope in more adaptive ways by learning how other women coped effectively with the side effects of chemotherapy. This could be achieved by developing a DVD whereby women who received chemotherapy as part of treatment for breast cancer share their experiences, and discuss how they cope with the specific side effects of treatment. Interventions that utilize vicarious experience through modelling have had some success but have not been consistently assessed for their ability to reduce distress (Lee, Robin Cohen, Edgar, Laizner, & Gagnon, 2006; Lev & Owen 2000; Lev, Paul, & Owen, 1999). The development of an intervention such as this will allow for an examination of the benefit of modelling in reducing distress and increasing self-efficacy and perceived control.

**Overall Summary**

Perceptions of illness are important for responding to the threat of cancer. They can influence worry about developing the disease in the future, as well as the emotional response to a diagnosis. The current research provides knowledge about
how components of the SRM determine cancer-related distress. Study 1a) examined risk and illness perceptions and found that they predict cancer worry in healthy women. In addition, risk perceptions partially mediated the relationship between illness perceptions and breast cancer worry. Despite this, risk and illness perceptions were poor predictors of breast self-examination and screening intentions. Study 1b) illustrated that differences in illness perceptions and cancer worry are reported in women with varying experience of breast cancer. Study 2 supported the SRM in that illness perceptions and coping were predictive of general and cancer-specific distress in women with breast cancer. In addition, the mediating role of coping was demonstrated, providing further evidence of the utility of the model. Study 3 explored the experience of coping with chemotherapy and provided insight into how coping appraisal can determine distress.

The interaction of risk and illness perceptions is a novel finding, and provides a better understanding of how these constructs can be conceptualised. The differences in distress and illness perceptions in women with varying levels of breast cancer experience highlights the importance of measuring illness perceptions in healthy women. A number of illness perceptions influential in breast cancer-related distress were identified, including illness coherence and control. Illness perceptions and coping were predictive of distress in women with breast cancer, but the relative contributions of these constructs differed over time, indicating that further clarification of the interplay of these constructs is warranted. The mediating role of coping on the illness perceptions and distress relationship provides further evidence for the importance of assessing both illness perceptions and coping together. Furthermore, the use of both qualitative and quantitative studies led to a better understanding of how women cope with breast cancer treatment, and provided an insight into potential interventions to reduce distress in future research.

The continued examination of risk and illness perceptions is required to develop a greater understanding of how these perceptions can determine behaviours such as screening adherence. The use of more longitudinal and comprehensive methodologies, including measures of illness perceptions, coping, and coping appraisal, are required to determine the full extent of the SRM in influencing distress in breast cancer. In addition, current findings suggest relevant intervention strategies to prepare women for chemotherapy in the future.
Chapter 6: Discussion


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APPENDICES

APPENDIX A.

Measures of Demographic and Medical Information, Screening Intentions, Breast Cancer Worry, and Risk Perceptions (Study 1a)

How old are you? 

Are you . . . ?

☐ Single ☐ Cohabiting ☐ Married ☐ Separated ☐ Divorced ☐ Widowed

Are you . . . ?

☐ Caucasian (White) ☐ African ☐ Asian ☐ Other

Are you working . . . ?

☐ Full-time ☐ Part-time ☐ Working in the home
☐ Semi-Retired ☐ Retired ☐ Not working ☐ Student

Medical History

Have you ever received a diagnosis of any type of cancer?

☐ No
☐ Yes

If yes, please specify which type of cancer:

Have you ever been diagnosed with a long term illness requiring treatment?

☐ No
☐ Yes

If yes, please specify what type(s) of illness:
Appendices

How old were you when you had your first menstrual period?

☐ Don’t know       ☐ 7-11 years
☐ 12-13 years       ☐ 14 years or older

Have you ever had children?  ☐ No    ☐ Yes
If yes, how old were you when your first child was born?

☐ Don’t know       ☐ less than 20 years  ☐ 20-24 years
☐ 25-29 years       ☐ 30 years or older

Have you ever had a breast biopsy?  ☐ Don’t know       ☐ No    ☐ Yes
If yes,
(a) How many breast biopsies (positive or negative) have you had?  
(b) Have you had a breast biopsy with atypical hyperplasia?

☐ Don’t know     ☐ No    ☐ Yes

Have any friends, colleagues, acquaintances been diagnosed with breast cancer?

☐ No
☐ Yes

Have any relatives (mother, sister, grandmother, aunt, daughter, niece) been diagnosed with any type of:

Breast cancer  ☐ Yes    ☐ No
Ovarian cancer  ☐ Yes    ☐ No
Other cancer(s)  ☐ Yes    ☐ No

If other, please specify which type(s):
Knowledge of Cancer

Have you ever studied or worked in a cancer related field? □ No □ Yes

If yes, did you . . .

□ Study a cancer related topic in college/ a course

□ Work for a cancer related charity or other organization

□ Work in the health services in a cancer related field

Please write in the box provided below what you think the symptoms of breast cancer are:
Breast Cancer Screening

Have you ever performed a breast self-examination? □ Yes □ No

If yes, how often you do check your breasts?
□ More than once a month □ Once a month □ Every few months
□ Once a year □ Less than once a year

How confident are you in your ability to perform breast self-examinations?
Not at all confident Not sure Very confident
1 2 3 4 5

Has your doctor ever recommended a mammogram (breast x-ray)?
□ Yes □ No □ Not sure

Have you ever had a mammogram? □ Yes □ No
If you have never had a mammogram, please answer QA; if you have had a mammogram, please answer QB-D.

QA. What was the most important factor in your decision not to have a mammogram?
□ Doctor’s recommendation against or lack of recommendation for
□ Magazine article or news report
□ Personal assessment of breast cancer risks
□ Personal assessment of benefits or harms
□ Cost of inconvenience
□ Fear of being diagnosed with cancer
□ Lack of concern
□ Too young to have a mammogram
□ Other ____________________________
QB. How many mammograms have you had? □ 1 □ 2 □ 3 or more

QC. How long has it been since your last mammogram?
□ Less than a year □ 1-2 years □ more than 2 years □ not sure

QD. What was the most important factor in your decision to have a mammogram?
□ Doctor’s recommendation
□ Invitation for a mammogram through BreastCheck
□ Family member or friend’s recommendation
□ Magazine article or news report
□ Personal assessment of breast cancer risks
□ Personal assessment of benefits or harms
□ Other ________________________________

Do you intend to obtain a mammogram through the free breast cancer screening service BreastCheck, when you are invited by them in the future?

<table>
<thead>
<tr>
<th>Definitely not</th>
<th>not sure</th>
<th>Definitely yes</th>
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<tbody>
<tr>
<td>0</td>
<td>1</td>
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<td>3</td>
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</table>

Please rate the following statements about breast screening.

*Breast cancer screening is:*

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Not sure</th>
<th>Agree</th>
<th>Strongly agree</th>
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<tr>
<td>Easy</td>
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<tr>
<td>Useful</td>
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<tr>
<td>Uncomfortable</td>
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<tr>
<td>Accurate in detecting breast cancer</td>
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<tr>
<td>Worrying</td>
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<tr>
<td>Important</td>
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<td></td>
</tr>
<tr>
<td>Inconvenient</td>
<td></td>
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<tr>
<td>Painful</td>
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<tr>
<td>Reassuring</td>
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<tr>
<td>Embarrassing</td>
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</table>
Appendices

Worry about Breast Cancer

How **anxious** are you of getting breast cancer in your lifetime?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Somewhat</th>
<th>Extremely</th>
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<tr>
<td>1</td>
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<td>4</td>
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</table>

How **fearful** are you of getting breast cancer in your lifetime?

<table>
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<tr>
<th>Not at all</th>
<th>Somewhat</th>
<th>Extremely</th>
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<td>4</td>
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</tbody>
</table>

How **concerned** are you of getting breast cancer in your lifetime?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Somewhat</th>
<th>Extremely</th>
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<tbody>
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<td>1</td>
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<td>4</td>
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</tbody>
</table>

How **worried** are you of getting breast cancer in your lifetime?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Somewhat</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
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<td>4</td>
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<td>6</td>
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</tbody>
</table>

How **often** do you worry about developing breast cancer?

<table>
<thead>
<tr>
<th>Never/rarely</th>
<th>Sometimes</th>
<th>Very often</th>
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<tbody>
<tr>
<td>1</td>
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<td>7</td>
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</table>

How much does worrying about developing breast cancer interfere with your everyday life?

<table>
<thead>
<tr>
<th>Never/rarely</th>
<th>Sometimes</th>
<th>Very often</th>
</tr>
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<tbody>
<tr>
<td>1</td>
<td>2</td>
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<tr>
<td>7</td>
<td></td>
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</table>
Likelihood of developing Breast Cancer

The following six questions ask you about what you think the likelihood is of you developing breast cancer in the future. The questions may seem similar, but please read them carefully before answering.

1. What do you think the likelihood is of you developing breast cancer in your lifetime?
   
   Please give a value between 0% and 100%, where 0 means you definitely will not be diagnosed with cancer and 100 means you definitely will be diagnosed with cancer. *You can pick any number between 0 and 100.*

2. What do you think the likelihood is of you developing breast cancer in the next five years?
   
   Please give a value between 0% and 100%, where 0 means you definitely will not be diagnosed with cancer and 100 means you definitely will be diagnosed with cancer. *You can pick any number between 0 and 100.*

3. How would you rate your chance of developing breast cancer?
   Please circle your answer.
   
   Very low   moderately low    neither high nor low   moderately high   very high

4. What is the likelihood of you having breast cancer someday?
   
   □ 1 in 100   □ 1 in 50   □ 1 in 25
   □ 1 in 10   □ 1 in 5   □ 1 in 2
   □ No chance

5. How vulnerable do you think you are to getting breast cancer at some point in your life? Please circle your answer.
   
   Not at all                     Extremely vulnerable
   
   1  2  3  4  5  6  7  

6. How severe do you think breast cancer would be if you developed it at some point in your life?
Appendices

Please circle your answer.

Not at all          Extremely severe

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

The following questions ask you about what you think the likelihood is of the average woman (similar to you in age and risk factors) developing breast cancer in the future. Again, please read each question carefully before answering.

7. What do you think the average woman’s likelihood is of developing breast cancer in her lifetime?
Please give a value between 0% and 100%, where 0 means you definitely will not be diagnosed with cancer and 100 means you definitely will be diagnosed with cancer. You can pick any number between 0 and 100.

8. How would you rate the chance of an average woman developing breast cancer?
Please circle your answer.

Very low             moderately low     neither high nor low      moderately high      very high

9. Overall, how do you think your chance of developing breast cancer compares to the average woman of your age?
Please circle your answer.

Much lower          about the same       much higher

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

10. What is the likelihood of an average woman having breast cancer someday?

☐ 1 in 100          ☐ 1 in 50           ☐ 1 in 25
☐ 1 in 10          ☐ 1 in 5            ☐ 1 in 2
☐ No chance
APPENDIX B

Measures of Breast Cancer Distress, Demographic, and Knowledge of Breast Cancer Questions (Study 2)

Please answer the following questions about how you feel about your diagnosis of breast cancer.

<table>
<thead>
<tr>
<th>How <strong>anxious</strong> are you?</th>
<th>Somewhat</th>
<th>Extremely</th>
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<tbody>
<tr>
<td>Not at all</td>
<td>1</td>
<td>2</td>
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<tr>
<td>Somewhat</td>
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<tr>
<td>Extremely</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>How <strong>fearful</strong> are you?</th>
<th>Somewhat</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
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<td>2</td>
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<tr>
<td>Extremely</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>How <strong>concerned</strong> are you?</th>
<th>Somewhat</th>
<th>Extremely</th>
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<tbody>
<tr>
<td>Not at all</td>
<td>1</td>
<td>2</td>
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<tr>
<td>Extremely</td>
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<table>
<thead>
<tr>
<th>How <strong>worried</strong> are you?</th>
<th>Somewhat</th>
<th>Extremely</th>
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<tbody>
<tr>
<td>Not at all</td>
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<tr>
<td>Extremely</td>
<td>5</td>
<td></td>
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</table>
Appendices

Demographic Details

How old are you?  

Are you . . . ?

☐ Single  ☐ Cohabiting  ☐ Married  ☐ Separated  ☐ Divorced  ☐ Widowed

Are you . . . ?

☐ Caucasian (White)  ☐ African  ☐ Asian  ☐ Other

Are you working . . . ?

☐ Full-time  ☐ Part-time  ☐ Working in the home  ☐ Semi-Retired
☐ Retired  ☐ Not working  ☐ Student

Medical History

Please state your diagnosis (if known):

Please write in the box provided below of any symptoms you experienced before you were diagnosed with breast cancer:

How long have you been experiencing symptoms?
Knowledge of Breast Cancer

Have any friends, colleagues, acquaintances been diagnosed with breast cancer?

□ No
□ Yes

Have you ever studied or worked in a cancer related field? □ No □ Yes

If yes, did you . . . (please tick all that apply)

□ Study a cancer related topic in college/ a course

□ Work for a cancer related charity or other organization

□ Work in the health services in a cancer related field

Marital status
Single Cohabiting Married Separated Divorced Widowed

Employment status
Full-time Part-time Working in the home Unemployed Retired

Family history
Has anyone in your family previously has a diagnosis of breast cancer? Yes No
If yes, please state who (e.g. mother, sister)

Treatment
When were you diagnosed?

Have you finished your treatment for breast cancer? Yes No

If yes, when did you finish your treatment?

Please circle the kind of surgery and treatment you received below.
Lumpectomy (breast conserving surgery) Yes No
mastectomy with reconstruction Yes No
mastectomy without reconstruction Yes No
Appendices

Did you have **all** your lymph nodes removed (axillary clearance)?  Yes  No

Did you receive/are you receiving radiotherapy?  Yes  No
If **yes**, how many treatments did you have?

Did you receive/are you receiving chemotherapy?  Yes  No
If **yes**, how many treatments did you have?

Did you receive / are you receiving hormone treatment?  Yes  No
If **yes**, please state the name of the treatment (s)
APPENDIX C

Participant Information Sheet Study 1
Perceptions of Breast Cancer Study

You are being invited to participate in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. This Participant Information Sheet will tell you about the purpose, risks and benefits of this research study. If you agree to take part, we will ask you to sign a Consent Form. If there is anything that you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read it. You should only consent to participate in this research study when you understand what is being asked of you, and you have had enough time to think about your decision.

Purpose of the Study
This study is examining the attitudes and knowledge of breast cancer in women in Ireland. How women think about breast cancer may influence how they respond to others with breast cancer and to a diagnosis themselves. The research aims to measure knowledge and attitudes of both women who have breast cancer and women from the general population, to see if there are differences in the way in which breast cancer is perceived. All women over 18 years of age are being invited to take part. The information you give will help us to highlight how breast cancer is understood and will improve the care of hundreds of women in the future.

What will be involved if I agree to take part in this study?
If you agree to take part in this study the researcher will ask you to complete a set of relatively short questionnaires. The questionnaires include questions about what you think are the consequences and causes of breast cancer, your family history of breast cancer, the likelihood of developing cancer, and questions about how you feel in general. This will take approximately 30 minutes to complete.

What are the benefits of taking part?
This information will help us to identify the way in which breast cancer is understood and identify the kind of support that would be beneficial to women at different times during breast cancer and treatment. This information will also help us improve services for women with breast cancer in the future.

What are the risks of taking part?
Whilst there are no known risks for participating, you may find that answering some of the questions may make you upset or distressed. If you need to discuss any issues that are brought up by the study, contact details are included below for free, confidential advice and support.

Can I withdraw from the study?
Even if you have agreed to take part in the study you are free to withdraw at any stage without having to explain why, without penalty or consequence.

Confidentiality
All information given to the researcher will be treated in the strictest confidence. The information will also be stored in a way that protects your identity. Your name will not appear in any report resulting from this study. A research number, but no name, will appear on all of the completed questionnaires. Individuals will not be identifiable from the details in the reports resulting from this study.

If you have any questions please contact Andrea Gibbons at: Department of Psychology, NUI Galway, phone: (091) 495123, email:a.gibbons2@nuigalway.ie

If you have concerns that you wish to discuss with an independent party, you may contact the Secretary of the NUI Galway Research Ethics Committee, Padraic De Burca c/o Office of the Vice President for Research, ethics@nuigalway.ie.

If you feel that you have been affected in any way by the topics raised by the research, you can contact the Samaritans, who provide free confidential emotional support, by phone (1850) 609090 or by email at jo@samaritans.org.

Alternatively, there are specific counselling and support service services provided by Cancer Care West for people who are affected by cancer. Contact them at on (091) 545000, or call in to their support centre at Inis Aoibhinn, Costello Road entrance, University College Hospital Galway.

I would like to remind you that you are welcome to contact Ms. Gibbons if you have any concerns or questions about this research. Again, please note that you are free to refuse to take part in the study without any disadvantage or discontinue your participation at any point without penalty or consequence.

Thank you for reading this.
APPENDIX D

Participant Consent Form Study 1

Title of research: Perceptions of Breast Cancer Study
Researcher: Andrea Gibbons, BA, M.Psych.Sc.

Please place a circle round either Yes or No

I have read and understood the information sheet about the study which is examining the attitudes and knowledge of breast cancer

Yes  No

I understand that I am free to withdraw from this study at any time, without giving any reasons, without my legal rights being affected.

Yes  No

I understand that any information I give to the researcher will be treated in the strictest confidence.

Yes  No

I understand that I can ask the researcher questions about the study at any time.

Yes  No

I agree to take part in this study

Yes  No

I, the undersigned, agree to take part in this study examining attitudes and knowledge to breast cancer.

____________________ ____________ ___________________________
Name of Participant  Date   Signature

____________________ ____________ ___________________________
Name of Researcher  Date   Signature
APPENDIX E

Participant Information Sheet Study 2
Perceptions of Breast Cancer Study

You are being invited to participate in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. This Participant Information Sheet will tell you about the purpose, risks and benefits of this research study. If you agree to take part, we will ask you to sign a Consent Form. If there is anything that you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read it. You should only consent to participate in this research study when you understand what is being asked of you, and you have had enough time to think about your decision.

Purpose of the Study
You are invited to join a study which is examining the psychological impact of dealing with the diagnosis and treatment of breast cancer. We know this is a difficult and distressing time for you but the information you give will help us to improve the care of hundreds of women with breast cancer in the future.

What will be involved if I agree to take part in this study?
If you agree to take part in this study you will be asked in the first instance to complete a set of relatively short questionnaires. This will take approximately 30 minutes to complete.

If you agree, certain aspects of your medical information will be made available to the researcher. This information will relate only to your symptoms and procedures related to the study, such as the time of your first symptoms and current medication or treatment.

Can I withdraw from the study?
Even if you have agreed to take part in the study you are free to withdraw at any stage without having to explain why. Withdrawal from the study will not affect your care in this hospital in any way.

What are the benefits of taking part?
This information will help us to identify the way in which breast cancer is understood and identify the kind of support that would be beneficial to women at different times during breast cancer and treatment. This information will also help us improve services for women with breast cancer in the future.

What are the risks of taking part?
Whilst there are no known risks for participating, you may find that answering some of the questions may make you upset or distressed. If you need to discuss any issues that are
brought up by the study, contact details are included below for free, confidential advice and support.

Confidentiality
All information given to the researcher will be treated in the strictest confidence. Your name will not appear in any report resulting from this study. A research number, but no name, will appear on all of the completed questionnaires. Individuals will not be identifiable from the details in the reports resulting from this study. If you have any questions about the study at any time, please contact Andrea Gibbons, School of Psychology, NUI Galway, phone: (091) 495123, email: a.gibbons2@nuigalway.com.

If you have concerns that you wish to discuss with an independent party, you may contact the Secretary of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, ethics@nuigalway.ie.

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Alternatively, there are specific counselling and support service services provided by Cancer Care West for people who are affected by cancer. Contact them at on (091) 545000, or call in to their support centre at 2 Seamus Quirke Rd, Westside, Galway.

I would like to remind you that you are welcome to contact Ms. Gibbons if you have any concerns or questions about this research. Again, please note that you are free to refuse to take part in the study without any disadvantage or discontinue your participation at any point without penalty or consequence.

Research Team
Andrea Gibbons, BA, M.Psych.Sc. Dr. AnnMarie Groarke, Prof. Ruth Curtis, Ms. Anne Marie Keane; School of Psychology, NUI, Galway. Mr. Karl Sweeney, Mr Ray McLaughlin, Prof Michael Kerin and the Department of Surgery; University Hospital, Galway
Title of research: Perceptions of Breast Cancer Study
Researcher: Andrea Gibbons, BA, M.Psych.Sc.

I have read and understood the information sheet about the study which is examining the attitudes and knowledge of breast cancer
Yes  No

I understand that I am free to withdraw from this study at any time, without giving any reasons, without my legal rights being affected.
Yes  No

I understand that any information I give to the researcher will be treated in the strictest confidence.
Yes  No

I understand that I can ask the researcher questions about the study at any time.
Yes  No

I give my permission for my medical information to be available to the researcher for the purposes of this study.
Yes  No

I agree to take part in this study
Yes  No

I, the undersigned, agree to take part in this study examining attitudes and knowledge to breast cancer.

Name of Participant ______________ Date ______________ Signature __________________

Name of Researcher ______________ Date ______________ Signature __________________
APPENDIX G

Participant Information Sheet Study 3

Perceptions of Breast Cancer Study

You are being invited to participate in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. This Participant Information Sheet will tell you about the purpose, risks and benefits of this research study. If you agree to take part, we will ask you to sign a Consent Form. If there is anything that you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read it. You should only consent to participate in this research study when you understand what is being asked of you, and you have had enough time to think about your decision.

Purpose of the Study
You are invited to join a study which is examining the psychological impact of dealing with the diagnosis and treatment of breast cancer. We know this is a difficult and distressing time for you but the information you give will help us to improve the care of hundreds of women with breast cancer in the future.

What will be involved if I agree to take part in this study?
If you agree to take part in this study you will be asked to engage in a causal discussion with a researcher about your experience of breast cancer and the treatment you received. It is anticipated that each discussion will be approximately 60 minutes in duration. The discussion will be tape-recorded and transcribed for analysis. The researcher may also take notes during the interview. However, if at any stage, you experience discomfort, due to any element of the research (e.g., the questions) you may withdraw at any time without penalty or consequence.

Can I withdraw from the study?
Even if you have agreed to take part in the study you are free to withdraw at any stage without having to explain why. Withdrawal from the study will not affect your care in this hospital in any way.

What are the benefits of taking part?
This information will help us to identify the way in which breast cancer is understood and identify the kind of support that would be beneficial to women at different times during breast cancer and treatment. This information will also help us improve services for women with breast cancer in the future, by developing a DVD of women sharing their experiences of breast cancer to others in the same position.

What are the risks of taking part?
Whilst there are no known risks for participating, you may find that answering some of the questions may make you upset or distressed. If you need to discuss any issues that are
brought up by the study, contact details are included below for free, confidential advice and support.

Confidentiality
All information given to the researcher will be treated in the strictest confidence. Your name will not appear in any report resulting from this study. A research number, but no name, will appear on all of the completed questionnaires. Individuals will not be identifiable from the details in the reports resulting from this study. If you have any questions about the study at any time, please contact Andrea Gibbons, School of Psychology, NUI Galway, phone: 087 9606163, email: a.gibbons2@nuigalway.ie.

If you have concerns that you wish to discuss with an independent party, you may contact the Secretary of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, ethics@nuigalway.ie.

If you feel that you have been affected in any way by the topics raised by the research, you can contact the Samaritans, who provide free confidential emotional support, by phone (1850) 609090 or by email at jo@samaritans.org.

Alternatively, there are specific counselling and support service services provided by Cancer Care West for people who are affected by cancer. Contact them at on (091) 545000, or call in to their support centre at 2 Seamus Quirke Rd, Westside, Galway.

I would like to remind you that you are welcome to contact Ms. Gibbons if you have any concerns or questions about this research. Again, please note that you are free to refuse to take part in the study without any disadvantage or discontinue your participation at any point without penalty or consequence.

Research Team
Andrea Gibbons, BA, M.Psych.Sc. Dr. AnnMarie Groarke, Prof. Ruth Curtis, Ms. Anne Marie Keane; School of Psychology, NUI, Galway. Mr. Karl Sweeney, Mr Ray McLaughlin, Prof Michael Kerin and the Department of Surgery; University Hospital, Galway
APPENDIX H

Invitation letters for Study 3

Dear Jane Smith,

Thank you for participating in our Perceptions of Breast Cancer Study. As you may recall, one aim of the study is to help us to understand the thoughts and feelings of women during the difficult time of diagnosis, treatment and the months following treatment. You very kindly completed a questionnaire for us when you were in the hospital, and one year later.

A small study is also being carried that aims to develop a DVD for women about to undergo chemotherapy. From your questionnaire, you indicated that you did receive chemotherapy treatment. I invite you to read the sheet enclosed about taking part in an interview about your experience of breast cancer treatment. The interviews would require roughly one hour of your time. If you consent the interview will be audio-recorded. The time of the interview and also where the interview takes place is flexible and can be arranged around your schedule so that it is as convenient as possible.

I realise that you have already given a considerable amount of your time already to this kind of research; and we are very grateful for that. I would ask that you consider whether or not you are interested in taking part in the interview study, and send the reply sheet in the envelope provided. If you have any further questions or concerns please contact me; my details are provided below. I want to stress, however, that you are under no obligation to take part; you can withdraw from the study at any time and that your decision to take part will not affect your treatment in the hospital in any way. As a token of our appreciation for your help, women who take part in the interview will receive a €25 One4All gift card.

Thank you for your time for reading this, and I hope to hear from you soon,

Yours sincerely

Andrea Gibbons
BA, M.Psych.Sc

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Galway
T: 087-9606163
E: a.gibbons2@nuigalway.ie / andrea.a.gibbons@gmail.com

Other members of the research project team: Dr. AnnMarie Groarke, Prof Ruth Curtis, Ms Anne Marie Keane (MLitt), School of Psychology, NUI Galway; Mr. Karl Sweeney, Prof Michael Kerin, Mr. Ray McLaughlin, Department of Surgery, University Hospital Galway
Dear Jane Smith,

My name is Andrea Gibbons; I am a Ph.D. student in the School of Psychology at NUI, Galway. My current research is examining the psychological impact of dealing with the diagnosis and treatment of breast cancer. You have received this envelope because I asked the breast care nurses in the University Hospital Galway to forward these research details to women who have recently received chemotherapy as part of their treatment for breast cancer.

I invite you to read the sheet enclosed about taking part in an interview about your experience of breast cancer treatment. The interviews would require roughly one hour of your time. If you consent the interview will be audio-recorded. The time of the interview and also where the interview takes place is flexible and can be arranged around your schedule so that it is as convenient as possible.

In terms of the benefits of this study, it is hoped that our results will broaden the understanding of how the experience of breast cancer, and educational materials such as booklets, DVDs, as well the services provided, can be improved.

All information that is collected from you, during the course of the research, will be kept strictly confidential (i.e., the researchers will keep secret any information collected about you) and will not be shared with anyone else.

I would ask that you consider whether or not you are interested in taking part in the interview study, and send the reply sheet in the envelope provided. If you have any further questions or concerns please contact me; my details are provided below. I want to stress, however, that you are under no obligation to take part; you can withdraw from the study at any time and that your decision to take part will not affect your treatment in the hospital in any way. As a token of our appreciation for your help, women who take part in the interview will receive a €25 One4All gift card.

Thank you for your time for reading this, and I hope to hear from you soon,

Yours sincerely

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APPENDIX I

Interview Schedule and Demographic Questions Study 3

- Can you please describe how you were diagnosed?
- What treatment did you have?
- What did you do to help yourself through it?
- What was the worst part of the experience?
- How did you deal with your worst times?
- What was the best part of the experience?
- What would you like to tell other women going through treatment?
- How has the experience of breast cancer changed your life?
## Demographic Information

**Age**

**Marital status**
- Single
- Cohabitating
- Married
- Separated
- Divorced
- Widowed

**Employment status**
- Full-time
- Part-time
- Working in the home
- Unemployed
- Retired

**Treatment**

**When were you diagnosed?**

**Have you finished your treatment for breast cancer?**
- Yes
- No

**If yes, when did you finish your treatment?**

**Please circle the kind of surgery and treatment you received below.**

- **Lumpectomy (breast conserving surgery)**
  - Yes
  - No
- **Mastectomy with reconstruction**
  - Yes
  - No
- **Mastectomy without reconstruction**
  - Yes
  - No

- Did you have **all** your lymph nodes removed (axillary clearance)?
  - Yes
  - No

- Did you receive radiotherapy?
  - Yes
  - No

**If yes, how many treatments did you have?**

- Did you receive / are you receiving hormone treatment?
  - Yes
  - No
APPENDIX J

Summary Diagram of Data collection Flowchart

Study 1a)
Healthy women from the general population
N = 978

- 30 excluded
  - 28 ineligible:
    - 25 previous history of cancer
    - 3 <18 years

Completed Questionnaire
N = 948

Study 1b)
Subset of 99 women from Study 1A (≥ 50 yrs)
Subset of 60 women from Study 2 (12 months post-diagnosis)

Study 2
Women with breast cancer
N = 418

- 41 excluded:
  - 27 ineligible
  - 14 declined to take part
  - 272 not returned

Completed Questionnaire at 12mths Post-diagnosis
N = 60

Study 3
Women with breast cancer requiring chemotherapy
N = 50

- 23 excluded
  - 3 declined to take part
  - 3 too ill to participate
  - 17 no response
  - 7 not contacted

Completed Semi-structured interview
N = 20

Diagnosis Questionnaire (pre-treatment)
N = 105

- 22 not returned
- 23 not sent
### APPENDIX K. Tables of Summary of the Theme of Coping with Example Quotations

**Appendix K(a). Summary of the Theme of Behavioural Coping with Example Quotations**

<table>
<thead>
<tr>
<th>Sub-theme</th>
<th>Example Quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Anticipatory Coping</strong></td>
<td>What I did was, to prepare; I think if people are prepared in advance, particularly women who have a family to fill the freezer. Make sure you have everything done in portions, so if you don’t feel like eating, or doing anything, at least someone else has a meal, or you know you don’t have to deal with it (P9)</td>
</tr>
<tr>
<td></td>
<td>I had a wig already got. . . I did have it short, very short like you know going through the treatment (P3)</td>
</tr>
<tr>
<td></td>
<td>I had cut my hair, my hair was always kind of short anyway, so when I knew this was happening say, I went every two weeks and got it cut shorter and shorter so that by the time I was going in for the chemo it was, I’d really short hair (P2)</td>
</tr>
<tr>
<td><strong>Seeking Information</strong></td>
<td>I got those books in the hospital, you know there’s different books for all the, there’s one for radiotherapy, one for chemotherapy, one for everything really. I got those books, you know (P2)</td>
</tr>
<tr>
<td></td>
<td>You’ll always meet somebody else that’s in the same boat as yourself. So I think that was good to kinda be in touch with those people as well (P3)</td>
</tr>
<tr>
<td><strong>Self-care Behaviour</strong></td>
<td>I was very mindful of the fact that it was important to keep the healthy diet as well. I probably ate better when I was on chemo than I have ever eaten (P18)</td>
</tr>
<tr>
<td></td>
<td>But I made sure, I knew that it was important to eat well. So the oncologist said if you’re not able to eat, take a multivitamin. So I did, I took it every day, and I made sure that I ate breakfast, and lunch, and tea. Now I might not have eaten a lot, but I made sure I had that structure (P8)</td>
</tr>
<tr>
<td></td>
<td>But I think the water is important. Drink lots and lots of water. It’ll help flush out the effects and you’ll get over it quicker, d’you know (P3)</td>
</tr>
<tr>
<td><strong>Maintenance of Activities</strong></td>
<td>keep trying to keep your life as normal, I think, as possible. And keep doing the things that you always you know you did. Don’t let it totally change, you know, your, your routine and your life (P3)</td>
</tr>
<tr>
<td></td>
<td>Get on as normal as much as you can. Put on make-up in the morning or whatever time you get up at (P7)</td>
</tr>
</tbody>
</table>
## Appendix K(b). Summary of the Theme of Emotional Coping with Example Quotations

<table>
<thead>
<tr>
<th>Sub-theme</th>
<th>Example Quotations</th>
</tr>
</thead>
</table>
| **Refocusing Attention** | I went on holidays in between … It was the best thing I ever did, because I went home on the 7th July and I went in on the 8th for the results. So I didn’t really think about it when I was away, which was great (P18)  
I think the trip away was a good help as well. Something to look forward to; it did help a lot. Something out of the ordinary (P20) |
| **Reappraisal**   | my skin all over felt like silk. I’ve a problem with my jaw; it’s out of kilter. My jaw improved dramatically and my nails grew like never before; so there’s positives in it! (P12)  
When I was doing the chemo it was great with no plucking the eyebrows, shaving the legs or underarms, I saved a fortune in hair dye and in razors. I can’t go back to all that again *(laughs)*. That was the worst part of it, when that hair started to grow back (P15) |
| **Emotional Expression** | It was the first time I broke down then, up in the day care. I was there and one of the nurses, she’s a sister on the ward. She was talking to me and I just burst out crying. That was the first time from the day I was told I had it, that I actually cried. Even with my family or on my own, I never cried. I absolutely never cried. I just burst out that day; I couldn’t help it (P19)  
I think in hindsight, had I cried I would have been better treated. I didn’t because that's not my way. That’s not how I deal with it at all. I gave the impression that I was flying it and I was able to deal with it. I know I was dealing with it better than others but there were times when I wasn’t, and I found I stuck my head into the sand (P18)  
I would say that attitude is a lot to do with it. I found that my attitude was this is not going to best me! And thankfully it didn’t … positive attitude is everything. It really is. If you think that it’s going to be bad, then you’ll make it bad for yourself I think (P20) |
| **Seeking Support** | I did go to the cancer support centre … I’d go because I quite liked a chat with the other women, and they’d be saying how they felt and what food they couldn’t taste and what did they do … and it was great having a laugh to hear other people talking about it (P1)  
If there was a service that could put you in touch with someone who has been through it you know (P18) |
Appendices

Appendix K(c). Summary of the Theme of Coping Appraisal with Example Quotations

<table>
<thead>
<tr>
<th>Sub-theme</th>
<th>Example Quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coping Ability</td>
<td>I was very lucky. What I had was dealable with (P11)</td>
</tr>
<tr>
<td></td>
<td>It wasn’t anything that I couldn’t cope with. I kind of knew at that stage (P18)</td>
</tr>
<tr>
<td>Difficulties in Coping</td>
<td>I used to drink a lot of water but I actually found it a hell of an effort to drink water. I didn’t want it; the water was ok, but I just didn’t feel like drinking. I didn’t feel like taking anything down that was going to upset my stomach (P11)</td>
</tr>
<tr>
<td></td>
<td>Because my hair was, my head was tender with losing the hair so quick; I couldn’t wear the wig all the time. Or I’d only wear it a bit and then I’d take it off (P1)</td>
</tr>
<tr>
<td></td>
<td>I got a wig beforehand; I got a wig before I lost the hair at all. But I didn’t wear it much. I didn’t feel comfortable in it. I found it very tight. I wore it a few times if I was going out or if I really wanted to forget (P18)</td>
</tr>
<tr>
<td></td>
<td>The first time I wore it was actually Christmas day. My sister was having dinner for us all, and I said I’d make an effort and put this thing on. I found it so tight and so sore warm. You’d think it’s awful but you do get used to it, you get used to anything. But I used to just wear a scarf most of the time. I didn’t buy the little caps you could buy. I found them very warm and kind of tight (P6)</td>
</tr>
<tr>
<td>Transitional Coping</td>
<td>It’s so hard to get back to where you were over a year ago. You get all these bad habits, a year of bad habits, so it’s so hard to get back to where I was (P15)</td>
</tr>
<tr>
<td></td>
<td>When you have appointments every day for 6 weeks and then nothing. You might be thinking well what am I going to do now? (P20)</td>
</tr>
<tr>
<td></td>
<td>I remember whenever I left in March, the oncologist, they said ok I’ll see you in May. I was down on average twice a week, between the middle of December and end of March, and then it was “we’ll see you in May”. That’s like whipping the safety net away. I said you guys have dictated my diary since last June, and they had, and suddenly I thought what am I going to do now? It was a real weird cut-off almost (P18)</td>
</tr>
<tr>
<td></td>
<td>Then the other side; the chemotherapy and that are too, and the radiotherapy is that all the people you miss when treatment ceases, you get an awful shock too. That can let you go down as well if you let it. You’re back to reality and nobody else around you has cancer, or has had it. Everybody is back talking about normal things and everything else. All of a sudden you realise, God I don’t want to mention about being sick or they’ll think I’m looking for sympathy (P19)</td>
</tr>
<tr>
<td></td>
<td>But it was only afterwards when you’re finished all your treatment, you feel abandoned. Because you’re not racing to one appointment or the hospital or you know, you’re not racing around all the time trying to keep up with stuff. It’s then you kind of go’ I was sick?’ You know you end up in a heap (P9)</td>
</tr>
</tbody>
</table>
### APPENDIX L. List of Hypotheses

<table>
<thead>
<tr>
<th>Hypothesis</th>
<th>Fully Confirmed</th>
<th>Partially confirmed</th>
<th>Rejected</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Higher levels of general anxiety (state and trait anxiety) predicts greater breast cancer worry</td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Higher risk perceptions and lower optimism predicts greater breast cancer worry</td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. More negative illness perceptions (e.g. negative emotional representations, stronger illness identity) predicts greater breast cancer worry</td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Having a family history of breast cancer predicts greater screening intentions and greater breast self-examination (BSE)</td>
<td></td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>5. More experience with screening (doctor recommendation, number of mammograms received previously) and more positive screening attitudes will predict greater screening intentions and greater breast self-examination (BSE)</td>
<td></td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>6. More confidence in performing breast self-examination predicts screening intentions and greater breast self-examination (BSE)</td>
<td></td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>7. Greater breast cancer worry predicts higher screening intentions and greater breast self-examination (BSE)</td>
<td></td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>8. Higher risk perceptions and lower optimism predicts higher screening intentions and greater breast self-examination (BSE)</td>
<td></td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>9. More negative illness perceptions (e.g. negative emotional representations, stronger illness identity) predicts higher screening intentions and greater breast self-examination (BSE)</td>
<td></td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>10. Risk perceptions mediate the relationship between illness perceptions and breast cancer worry</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Risk perceptions mediate the relationship between optimism and breast cancer worry</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Women with a family history of breast cancer report greater breast cancer worry than women without a family history of breast cancer</td>
<td></td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>13. Women with a family history of breast cancer report differences in illness perceptions to women without a family history of breast cancer</td>
<td></td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>14. Women with a family history of breast cancer report higher risk perceptions than women without a family history of breast cancer</td>
<td></td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>15. There are differences in illness perceptions in healthy women with and without a family history of breast cancer, and in women with breast cancer</td>
<td></td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>16. There are differences in cancer-related distress, but not general distress, in healthy women with and without a family history of breast cancer, and in women with breast cancer</td>
<td></td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>17. At diagnosis, greater perceived stress predicts greater anxiety, depression, state anxiety, and cancer-related distress</td>
<td></td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>18. At diagnosis, medical variables, illness perceptions and coping strategies predict anxiety, depression, state anxiety, and cancer-related distress</td>
<td></td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>19. At 12 months post-diagnosis, baseline measures of medical variables, illness perceptions, and coping strategies, predicts anxiety, depression, state anxiety, and cancer-related distress</td>
<td></td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>20. Coping strategies mediate the relationship between illness perceptions and cancer-related distress</td>
<td></td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>21. Coping strategies mediate the relationship between illness perceptions and general distress (anxiety, depression)</td>
<td></td>
<td>√</td>
<td></td>
</tr>
</tbody>
</table>