ILLNESS PERCEPTIONS AND DISTRESS IN WOMEN AT INCREASED RISK OF BREAST CANCER

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Variation in the levels of distress in women at increased risk of breast cancer has been reported, yet there is limited understanding of the factors that are associated with heightened distress in this population. This study took a theoretical approach using Leventhal’s Self Regulatory Model (SRM) to understand variation in distress levels. The study examined the associations between perceptions of breast cancer and distress in women at increased risk of breast cancer, and a comparison sample with no experience of the disease in their social environment. Questionnaire data from 117 women at increased risk of breast cancer and 100 comparison women were analysed. Women at increased risk of breast cancer showed comparable levels of general distress but significantly higher levels of cancer specific distress than the comparison group. There were few differences in illness perceptions between the samples, although a number of cognitive perceptions of breast cancer were related to both general and cancer specific distress in the increased risk sample, but not in the comparison sample. The results suggest that the SRM provides a useful framework to explore the psychological response to genetic risk. Further research is required in this population to examine illness perceptions in more detail, validate quantitative measures of illness perceptions, and examine interactions between risk perception and the SRM constructs.

Keywords: Breast cancer; Psychological distress; Cancer risk; Illness perceptions; Self-regulatory model; Genetic risk

INTRODUCTION

Familial Breast Cancer

A family history of breast cancer has been recognised as a risk factor for the disease for many years. It has been estimated that about 5–10\% of breast cancer cases are caused by hereditary factors. Recent research has identified autosomal dominant genes that when mutated predispose the carrier to developing breast cancer (Futreal \textit{et al.}, 1994;...
Miki et al., 1994; Wooster et al., 1995). These genes do not show 100% penetrance, the lifetime risks associated with a mutation estimated as being between 60–80% (Collins, 1996; Struwing et al., 1997). Women identified as carrying the BRCA1 mutation, also have an increased risk of ovarian cancer (Ford et al., 1998). The role of environmental factors in phenotypic expression of risk has been unclear (Evans et al., 1994).

Although many women will have a relative who has suffered from breast cancer, only a small proportion of them are likely to be at increased risk of the disease (Mettlin, 1994). The risk criteria to identify women at increased risk of breast cancer include the number of affected relatives, relationship to these relatives and importantly, the age of the relatives at diagnosis (familial breast cancer occurs at a younger age than sporadic breast cancer) (e.g. Scottish Intercollegiate Guidelines Network [SIGN], 1998). Assessment of family history in order to obtain a genetic risk estimate can be difficult due to inaccuracy of self reported family history and medical records, and insufficient female family members to allow expression of the condition (Richards, 1999). Familial breast cancer clinics have been established in order to provide risk assessment and risk management for those women who are deemed to have a significant family history. There are no proven preventative options for breast cancer and therefore early detection is paramount in reducing mortality. The women at increased risk of breast cancer are offered regular mammography from when they are five years younger than the youngest age at which any relative was diagnosed with breast cancer, but at no younger than 35 years or older than 40 years (Scottish Executive, 2001). However, the effectiveness of screening younger women is controversial, and data are only beginning to emerge to support the effectiveness among younger women selected for their familial risk (Macmillan, 2000; Tilanus-Linthorst, Bartels, Obdeijn and Oudkerk, 2000). High risk women may be offered prophylactic bilateral mastectomy which has been found to be effective in reducing the incidence of breast cancer in BRCA1 or BRCA2 mutation carriers (Meijers-Heijboer et al., 2001). Chemoprevention is currently being offered within the context of a clinical trial and likely to produce distressing and debilitating side effects (Emery, Murphy and Lucassen, 2000). Women with a family history of breast cancer therefore face much uncertainty regarding if and when cancer would develop, and how they should manage that risk.

**Distress in Women at Increased Risk of Breast Cancer**

Given the ambiguous nature of breast cancer risk, information and uncertain management options, it is not surprising that high levels of psychological morbidity in women at increased risk of breast cancer have been reported (Kash, Holland, Halper and Miller, 1992; Lerman and Schwartz, 1993; Gagnon et al., 1996). However, other studies have reported that women with at least one first degree relative who has suffered from breast cancer show levels of distress comparable to controls without a family history of the disease (Wellisch, Gritz, Schain, Wang and Siau, 1991; Lerman, Kash and Stefánek, 1994; Lloyd et al., 1996; Zakowski et al., 1997). Prospective studies assessing the impact of genetic risk counselling for breast cancer on levels of general and cancer specific distress have also been inconsistent (Hopwood et al., 1998; Cull et al., 1999; Watson et al., 1999). The methodological differences between studies in terms of sampling and assessment methods may account for variation in the level of distress. However, it is clear that individual differences in the levels of distress exist and that subgroups of women
maintain high levels of anxiety and worries about breast cancer (Appleton, Fry, Rees, Rush and Cull, 2000).

There is limited understanding of the cause of variation in distress in women at increased risk of breast cancer and studies have tended to be exploratory and descriptive. A number of studies have been focused on the accuracy of risk perception and the associations between risk perception and the psychological response to risk (Lerman et al., 1994; Lloyd et al., 1996; Hopwood et al., 1998, 2001; Cull et al., 1999; Watson et al., 1999; Kent, Howie, Fletcher, Newbury-Ecob and Hosie, 2000). These studies have suggested that risk perception is positively associated with cancer specific distress. Other factors found to be associated with distress include, age (Lerman et al., 1994; Cull et al., 1999), optimism (Audrain et al., 1997), and coping style (Lerman et al., 1996; Audrain et al., 1997). A number of qualitative studies have also identified that women’s experiences of breast cancer in their family is strongly associated with an emotional response to their own risk (Wellisch et al., 1991, 1992, 1996; Chalmers and Thomson, 1996). A few theoretically driven studies aimed at predicting psychosocial response to risk have also been conducted. Further research is needed to explore the cause of distress in a theoretical manner in order to establish and examine causal associations that can identify factors amenable to intervention (Rees, Fry and Cull, 2001).

A Theoretical Understanding

One model from health psychology that can help put a theoretical light on this issue is Leventhal’s self regulatory model (SRM). This model proposes that individuals actively generate cognitive and emotional representations of health threats and that these representations guide and regulate behaviour (Leventhal et al., 1997). The model indicates that internal stimuli (e.g. the experience of symptoms) as well as stimuli from the environment (e.g. risk information, witnessing a relative’s illness) may trigger cognitive and emotional representations. Based on these representations individuals derive an action plan to cope with the threat they perceive. The success of a particular coping strategy is appraised and feeds back into both the representation and the action plan, which may be modified accordingly. The SRM, therefore, provides a relevant framework from which to understand women’s response to breast cancer risk for a number of reasons. Crucially, the SRM enables a greater understanding of the meaning of risk by focusing on what individuals perceive they are at risk of. It enables the exploration of both the cognitive and the emotive representations in determining outcome and also allows a focus on the emotional outcomes rather than the behavioural outcomes that are the focus of the Health Belief Model (Rosenstock, 1966; Becker, 1974) and Theory of Reasoned Action (Ajzen and Fishbein, 1980).

Initial work on the SRM suggested that cognitive illness representations were organised around five dimensions: identity (symptoms associated with the illness); time line (beliefs about the duration of the illness); consequences (beliefs about the effects); control/cure (beliefs about its controllability and recovery); and cause (perceived causes of the illness) (Leventhal et al., 1997). A quantitative measure, the Illness Perception Questionnaire (IPQ) was developed and revised to assess these dimensions (Weinman, Petrie, Moss-Morris and Horne, 1996; Moss-Morris et al., 2002). Work on the SRM has mainly focused on the cognitive component of the model, and a number of qualitative and quantitative studies across a range of patient population
and studies have demonstrated associations between illness perceptions and emotional, cognitive and behavioural responses to illness (e.g. Petrie, Weinman, Sharpe and Buckley, 1996; Scharloo et al., 1998; Heijmans, 1999; Jessop and Rutter, 2003; Llewellyn, Miners, Lee, Harrington and Weinman, 2003). For example, illness perceptions have been found to predict psychological well-being in patients with Chronic Fatigue Syndrome and Rheumatoid Arthritis (Heijmans and De Ridder, 1998; Murphy, Dickens, Creed and Bernstein, 1999); self-management of diabetes and osteoarthritis (Hampson, Glasgow and Toobert, 1990; Hampson, Glasgow and Zeiss, 1994); adherence to medication among patients with asthma and haemophilia (Jessop and Rutter, 2003; Llewellyn et al., 2003) and return to work after a Myocardial Infarction (Petrie et al., 1996). A recent meta-analysis of the studies is available (Hagger and Orbell, 2003).

In relation to breast cancer, Buick (1997) found that illness perceptions were important predictors of psychosocial response to treatment, independent of objective illness severity. Causal beliefs about breast cancer have also been associated with patients’ adjustment to illness (Taylor, Lichtman and Wood, 1984). Early work by Leventhal on breast cancer patients found that the patients’ representations of breast cancer varied as a reflection of their experience, including variations in type of carcinoma, natural history of the disease and treatment type (Leventhal, Easterling, Coon, Luchterhand and Love, 1986). Buick (1997) also found that women’s recommended treatment for breast cancer had a large impact on their perceptions of the disease. The women recommended for chemotherapy perceived breast cancer to be longer in duration and more severe than those patients recommended for radiation treatment.

Although the SRM has primarily been applied to understanding psychological response in physically ill patients, illness perceptions are also likely be important predictors of healthy individuals’ response to health-threats such as a genetic predisposition to cancer (DeCruyenaere, Evers-Kiebooms, Welkenhuysen, Denayer and Claes, 2000). Individuals with a family history of breast cancer are likely to have witnessed and been affected by the experience of relatives who have suffered from the disease. Some studies have described women at increased risk of breast cancer as having lived vicariously through their relative’s breast cancer and having shared the illness experience (Chalmers and Thomson, 1996). These experiences are likely to generate strong illness perceptions that guide women’s emotional and behavioural response to their own genetic risk (Rees et al., 2001). The SRM would suggest that women with different experiences of breast cancer will construct different representations of the disease and choose different coping strategies for dealing with risk (Rees et al., 2001; Rees, 2003). Using the SRM in this context may help us to understand and predict the levels of distress, the screening behaviour and the decisions about preventative options such as prophylactic surgery.

This study used the SRM as a framework to examine emotional adjustment in women at increased risk of breast cancer. The study focused on the cognitive representation component of the model and had three main objectives. Firstly, to compare illness perceptions of breast cancer in women at increased risk due to their family history and a comparison group of women with no familial experience of the disease. Secondly, to examine associations between illness perceptions and distress in women at increased risk of breast cancer and the comparison sample. Thirdly, to examine the predictive value of illness perceptions in determining level of distress in women at increased risk of breast cancer.
METHOD

Participants
The study design was a cross-sectional postal questionnaire.

Increased Risk Sample
The participants were 200 women, randomly selected, from the database held by the South East Scotland Familial Breast Cancer Clinic. These women were deemed to be at least ‘moderate’ increased risk of breast cancer by a clinician at the South East Scotland Familial Breast Cancer Clinic (this means two to three times the general population risk). These women had received genetic counselling, and were on an annual programme of mammography and clinical breast examination. Prior to the selection, women on the database were excluded for the following reasons to ensure that the sample was as homogeneous as possible in respect to factors that may influence perceptions of breast cancer:

- Ovarian family history;
- Participation in chemo-prevention;
- Received genetic testing;
- Received preventative surgery.

Comparison Sample
The participants were 592 women who were identified from the Community Health Index at Lothian Health Board. This is a register of all individuals registered with GPs in the Lothian region of South East Scotland. These women were selected on the basis of their age and postcode sector in order that the sample was comparable to the increased risk sample on socio-demographic factors (e.g. age, education and ethnicity). These factors may influence illness perceptions (Klonoff and Landrine, 1994). For each woman at increased risk of breast cancer, three women with comparable age and postcode details were sought.

Women who self reported any experiences of breast cancer in their family, friends, work or ‘other’ experiences of breast cancer were excluded, so that the remaining sample reflected a sample of women in the general population without any experience of breast cancer in their social environment.

Additional Exclusion Criteria
In both the samples, prior to contacting the participants, the GPs of those women were contacted. The GPs were provided with a study information sheet and were asked to contact the researcher, if they considered any patient to be unsuitable for the study. The GPs were specifically asked to check the following exclusion criteria and to inform the researcher if the patient:

- Had a previous diagnosis of cancer in the past;
- Was currently undergoing investigation for cancer;
- Was currently suffering from any other serious illness;
- Was currently suffering from alcoholism, schizophrenia or organic brain damage.
Participants who were eligible for the study were sent an information sheet and a consent form. The women who consented were sent a questionnaire. A reminder was sent, if the questionnaire was not returned within 3 weeks.

**Test Retest**

The women in the increased risk sample who had returned their questionnaire without a reminder were followed up within 3 months, with an additional questionnaire, in order to obtain a test–retest reliability data.

**Measures**

**Illness Perceptions**

The Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002) is a theoretically derived measure, designed to assess dimensions of illness perceptions (identity, time line, consequences, control and cause) across a range of illnesses (Weinman et al., 1996; Moss-Morris et al., 2002). The measure was recently revised to include measures of perceptions of duration of illness (‘time acute/chronic’) and fluctuation in illness over time (‘time line cyclical’). In addition, the revised version also distinguishes perceptions of ‘treatment control’ and ‘personal control’ over illness. The revised version includes a new measures of ‘illness coherence’ – how clear and comprehensive an individual feels her illness to be. A new measure of ‘emotional representations’ is also included (Moss-Morris et al., 2002). The emotional representations subscale was not included in this analysis, since the aim of the study is to determine the contribution of cognitive representations of breast cancer on emotional adjustment. Including a measure of emotional representations as an independent variable would confound the outcome variables. The 50-item version of the IPQ-R was available during the design phase of this study and was adapted and reworded to make it appropriate for the healthy women at increased risk of breast cancer. Participants were asked to report their personal views about breast cancer rather than referring to their perceptions of an illness personally affecting them. For example: ‘My illness has serious financial consequences’ was replaced with ‘Breast cancer has serious financial consequences’; ‘My illness will last for a long time’ was replaced with ‘Breast cancer lasts for a long time’.

Identity is assessed using a 17-item symptom checklist. Following previous research on perceptions of breast cancer patients (Buick, 1996), discussions with breast cancer consultants and women at increased risk, breast cancer specific items were generated and added to the existing checklist. These included (‘hard or tender growths in body’, ‘soreness in body’, ‘skin changes’). Causal beliefs are assessed individually. Participants endorse 19 items, referring to the causes of breast cancer on a 5-point scale ranging from ‘strongly disagree’ to ‘strongly agree’. The item ‘hormonal’ was added to the cause subscale since oestrogen has been associated with breast cancer development (Vogel, 2000). The items for the remaining subscales are presented in a random order. Responses are rated on a 5-point scale from ‘strongly disagree’ to ‘strongly agree’. Subscale scores are the mean of items (after reverse scoring as necessary). Subscales with missing items are not computed. The number of items, internal
reliability (Cronbach’s alpha) and test–retest reliability for each subscale in the increased risk sample is outlined in Table I. The adapted IPQ-R was piloted on 11 women at increased risk of breast cancer to ensure that all items were relevant and understood appropriately. A copy of the adapted questionnaire is available from the authors.

**Psychological Well-being**

*General distress* The General Health Questionnaire 30-item version (GHQ-30) (Goldberg and Williams, 1998) is a well-validated self-administered screening test aimed at detecting psychiatric disorder in community and non-psychiatric clinical settings. The participants respond to thirty statements about their general health over the past few weeks on a four-point scale. The GHQ-30 was scored using both, the Likert method (0, 1, 2, 3) to investigate individual differences in levels of distress and the ‘alternative’ scoring system (0, 0, 1, 1) using a cut off score of >5 to determine prevalence of ‘case level’ of distress that warrants further clinical assessment (Goldberg and Williams 1998).

*Specific cancer related distress* The Cancer Worry Scale (Watson et al., 1999) is a 6-item scale (adapted from four single items, Lerman et al., 1991a,b), that assesses the frequency of cancer worries and the degree to which these worries affect mood and daily activities. Items are scored from 1–4 and summed for a total score. The scale has been used in populations at increased risk of cancer and shows good internal reliability (Brain, Norman, Gray and Mansel, 1999; Hopwood et al., 2001). Cronbach alpha in this study was 0.83, and test–retest reliability was $r = 0.74$, $p < 0.001$.

**Risk Perception**

A single item ‘How likely do you feel it is that you will develop breast cancer in your lifetime?’ rated on a 5-point Likert scale (1, ‘very unlikely’; 2, ‘unlikely’; 3, ‘likely’; 4, ‘very likely’; 5, ‘extremely likely’).

**Statistical Analysis**

Chi-square test was used to test for differences in categorical variables (GHQ ‘caseness’) and $t$-tests were used to test for differences on continuous variables (GHQ Likert score and cancer worry score).
RESULTS

Response Rates and Background Demographics

In the increased risk sample, 16 women were excluded by the GP before questionnaires were administered. One hundred and eighty-four women were invited to take part in the study and 117 women returned their questionnaire, giving a response rate of 64%. Ninety-nine of these women returned the questionnaire without a reminder and were sent a follow-up questionnaire to obtain test–retest data. Seventy-four of these women (75%) returned this questionnaire.

In the general population sample, 45 women were excluded by the GP. Replacements were found for 15 of these women. Therefore, 562 women were invited to take part in the study and 258 returned the questionnaires giving a response rate of 46%. Two of these questionnaires were excluded due to protocol violation (they reported to have experienced cancer themselves). From the 256 responses that were retained for analysis, 100 did not report any experience of breast cancer in family, friends or at work. These 100 women formed the comparison sample.

Almost 100% of women in both samples were Caucasian. Both samples were comparable on socio-demographic variables (age, education levels, marital status, and maternity). The characteristics of the sample are provided in Table II. Both samples consisted of well-educated, middle aged women, a majority of whom were married with children.

Women in the increased risk sample were significantly more likely to believe they will develop breast cancer in their lifetime than the comparison sample ($t = 7.48, df = 211, p < 0.001$). In the increased risk sample 77% believed they were ‘likely’, ‘very likely’ or ‘extremely likely’ to develop breast cancer in their lifetime compared with 33% in the comparison sample.

Differences Between the Samples: Distress

Table III shows a descriptive data for the psychological well-being measures in each sample and the differences between the samples. The results show that the samples

<table>
<thead>
<tr>
<th>Table II</th>
<th>Sample characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Variable</strong></td>
<td><strong>Increased risk sample</strong></td>
</tr>
<tr>
<td></td>
<td>$(n=117)$</td>
</tr>
<tr>
<td>Age (years)</td>
<td>Mean = 40.4 (7.09)</td>
</tr>
<tr>
<td>% educated beyond 18</td>
<td>44.5%</td>
</tr>
<tr>
<td>% married or living with a partner</td>
<td>88%</td>
</tr>
<tr>
<td>% with at least one child</td>
<td>71%</td>
</tr>
</tbody>
</table>

* * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

<table>
<thead>
<tr>
<th>Table III</th>
<th>Levels of distress in each sample</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Distress measure</strong></td>
<td><strong>Increased risk sample</strong> $(n=117)$. Mean (SD)</td>
</tr>
<tr>
<td>GHQ score</td>
<td>27.0 (11.86)</td>
</tr>
<tr>
<td>Cancer worry scale</td>
<td>10.7 (2.58)</td>
</tr>
</tbody>
</table>

* * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$
did not show different levels of general distress \( (p < 0.05) \). There was also no difference in the proportion of GHQ cases in each sample \( (\chi^2 = 0.009, \text{df} = 1, p = 0.93) \). However, the increased risk sample reported significantly higher levels of cancer specific distress than the comparison sample \( (p < 0.001) \).

**Differences Between the Samples: Illness Perceptions**

Table IV shows the mean scores for each of the IPQ-R subscales and the causal items for each sample and differences between the samples. The results indicate that women at increased risk of breast cancer had a more coherent understanding of breast cancer than the comparison group \( (p < 0.001) \). The results also suggest that women at increased risk of breast cancer viewed the consequences of breast cancer to be more severe than the comparison group \( (p = 0.05) \). However, the actual difference between scores on the consequences measure was small. The samples differed on a number of causal beliefs. Women at increased risk of breast cancer were more likely to believe that ‘hereditary’, ‘ageing’ and ‘hormonal factors’ were the causes of breast cancer, and less likely to believe that ‘poor medical care in the past’ or ‘a germ or virus’ were causes of breast cancer \( (p < 0.05) \).

**TABLE IV** Illness perceptions in each sample

<table>
<thead>
<tr>
<th>IPQ-R subscale</th>
<th>Increased risk sample ( (n = 117) ) Mean (SD)</th>
<th>Comparison sample ( (n = 100) ) Mean (SD)</th>
<th>Difference test (df)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
<td>4.44 (2.25)</td>
<td>4.98 (2.88)</td>
<td>( t = -1.56 ) (215)</td>
</tr>
<tr>
<td>Timeline acute</td>
<td>3.27 (0.53)</td>
<td>3.19 (0.49)</td>
<td>( t = 0.99 ) (204)</td>
</tr>
<tr>
<td>Consequences</td>
<td>3.94 (0.38)</td>
<td>3.83 (0.41)</td>
<td>( t = 1.97 ) (201)*</td>
</tr>
<tr>
<td>Personal control</td>
<td>3.25 (0.60)</td>
<td>3.25 (0.43)</td>
<td>( t = 0.078 ) (200)</td>
</tr>
<tr>
<td>Treatment control</td>
<td>3.62 (0.52)</td>
<td>3.62 (0.36)</td>
<td>( t = -0.088 ) (205)</td>
</tr>
<tr>
<td>Illness coherence</td>
<td>2.45 (0.69)</td>
<td>3.07 (0.64)</td>
<td>( t = -6.65 ) (203)**</td>
</tr>
<tr>
<td>Causal items:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress or worry</td>
<td>3.16 (0.99)</td>
<td>3.19 (0.91)</td>
<td>( t = -0.25 ) (211)</td>
</tr>
<tr>
<td>Hereditary-it runs in the family</td>
<td>4.56 (0.49)</td>
<td>4.24 (0.64)</td>
<td>( t = 4.45 ) (df 214)**</td>
</tr>
<tr>
<td>A germ or virus</td>
<td>2.12 (0.93)</td>
<td>2.36 (0.83)</td>
<td>( t = -1.98 ) (210)*</td>
</tr>
<tr>
<td>Diet or eating habits</td>
<td>3.31 (0.98)</td>
<td>3.08 (0.93)</td>
<td>( t = 1.75 ) (210)</td>
</tr>
<tr>
<td>Chance or bad luck</td>
<td>3.03 (1.12)</td>
<td>2.96 (1.04)</td>
<td>( t = 0.51 ) (212)</td>
</tr>
<tr>
<td>Poor medical care in the past</td>
<td>2.26 (0.92)</td>
<td>2.60 (0.84)</td>
<td>( t = -2.85 ) (211)**</td>
</tr>
<tr>
<td>Pollution in the environment</td>
<td>2.97 (0.91)</td>
<td>3.07 (0.83)</td>
<td>( t = -0.84 ) (211)</td>
</tr>
<tr>
<td>Patient’s own behaviour</td>
<td>2.53 (0.95)</td>
<td>2.59 (0.87)</td>
<td>( t = -0.502 ) (211)</td>
</tr>
<tr>
<td>Patient’s mental attitude, e.g. thinking about life negatively</td>
<td>2.54 (0.93)</td>
<td>2.53 (0.83)</td>
<td>( t = 0.059 ) (211)</td>
</tr>
<tr>
<td>Family problems or worries causes breast cancer</td>
<td>2.52 (0.87)</td>
<td>2.54 (0.83)</td>
<td>( t = -0.12 ) (210)</td>
</tr>
<tr>
<td>Overwork</td>
<td>2.37 (0.75)</td>
<td>2.47 (0.73)</td>
<td>( t = -1.04 ) (212)</td>
</tr>
<tr>
<td>Emotional state e.g. feeling down, lonely, anxious, empty</td>
<td>2.5 (0.85)</td>
<td>2.5 (0.84)</td>
<td>( t = -0.044 ) (211)</td>
</tr>
<tr>
<td>Ageing</td>
<td>3.28 (0.93)</td>
<td>3.00 (0.91)</td>
<td>( t = 2.18 ) (212)*</td>
</tr>
<tr>
<td>Alcohol</td>
<td>2.68 (0.91)</td>
<td>2.77 (0.84)</td>
<td>( t = -0.72 ) (209)</td>
</tr>
<tr>
<td>Smoking</td>
<td>3.41 (0.99)</td>
<td>3.49 (0.87)</td>
<td>( t = -0.66 ) (210)</td>
</tr>
<tr>
<td>Accident or injury</td>
<td>2.61 (0.95)</td>
<td>2.76 (0.96)</td>
<td>( t = -1.15 ) (209)</td>
</tr>
<tr>
<td>Patient’s personality</td>
<td>2.21 (0.78)</td>
<td>2.16 (0.66)</td>
<td>( t = 0.4 ) (212)</td>
</tr>
<tr>
<td>Altered immunity</td>
<td>2.89 (1.05)</td>
<td>3.01 (0.83)</td>
<td>( t = -0.86 ) (213)</td>
</tr>
<tr>
<td>Hormonal</td>
<td>3.69 (0.75)</td>
<td>3.46 (0.81)</td>
<td>( t = 2.19 ) (213)*</td>
</tr>
</tbody>
</table>

*\( p < 0.05 \); **\( p < 0.01 \); ***\( p < 0.001 \)
Associations Between Illness Perceptions and Distress

Table V shows the Pearson correlations between illness perceptions, age, risk perceptions and distress measures in both the samples. The results indicate that both general distress and cancer worry are associated with higher scores on the identity, timeline acute and consequences subscales in the increased risk sample \( (p < 0.05) \). This suggests that women at increased risk of breast cancer with higher levels of distress, view breast cancer as more chronic, more severe, and associate more symptoms with the disease. In the comparison sample, no subscales were associated with general distress and only the identity dimension was positively associated with cancer worry \( (p < 0.001) \). Due to the large number of causal items a more stringent significance level \( (p < 0.01) \) was adopted. No causal items were found to be significantly correlated distress measures in either sample \( (p < 0.01) \).

**Predicting Distress**

Simultaneous multiple regression models were computed in order to examine the predictive value of illness perception and risk perception on general distress and cancer worry in both samples. The models had two steps. In the first step, age was entered as a control variable and the IPQ-R variables were entered. In the second step, risk perception was added in order to determine its remaining contribution. Tables VI and VII summarise the results.

The results showed that the models were not significant in predicting general distress in either sample \( (p < 0.05) \). The proportion of variance accounted for by illness perception variables was low in both samples and risk perception was not a significant predictor. The only significant cognitive variables were the identity dimension in the increased risk sample and the illness coherence dimension in the comparison sample. This suggests that identifying more symptoms of breast cancer was predictive of greater general distress in the increased risk sample and that having a less clear understanding of breast cancer was predictive of general distress in the comparison sample. In the comparison sample age was also a predictor of general distress. Increased age significantly predicted heightened distress in this sample.

The models were significant in predicting cancer worry. The final model in the increased risk sample accounted for 26% of the variance in cancer worry \( (p < 0.001) \).
However, risk perception was found to be the only significant predictive cognitive variable. Higher perceived risk was predictive of higher levels of cancer worry. Age was also a significant predictor of cancer worry in this sample. Younger age was predictive of heightened cancer worry. In the comparison sample the final model accounted for 14% of variance in cancer worry ($p < 0.05$). However, in this sample risk perception was not found to be a significant predictor. The only cognitive variable that was predictive of cancer worry in this sample was the identity subscale. Identifying more symptoms of breast cancer was predictive of greater cancer worry in the comparison sample.

**DISCUSSION**

This study was theoretically driven to utilise the SRM as a framework to understand variation in the psychological response to genetic risk of breast cancer. The study focused on one element of the model-illness perceptions, and aimed to examine associations between illness perceptions and distress in women at increased risk of breast cancer, and a comparison sample with no experience of breast cancer in their social environment.
The results are in line with previous research which indicates that women attending UK familial cancer clinics show levels of general distress comparable to women in the general population (Cull et al., 1999; Cull, Fry, Rush and Steel, 2001). This may verify previous suggestions that global measures of distress do not capture the specific sources of distress in women at increased risk of breast cancer and that measures of cancer specific related anxiety are more informative (Hopwood et al., 1998; Kent et al., 2000; Thewes, Meiser and Hickie, 2001). However, the clinical significance of levels of cancer specific distress remains unknown and normative data are not yet available. There are concerns that measures of cancer worry reflect a realistic response to the situation rather than morbid anxiety (Coyne, Benazon, Gaba, Calzone and Weber, 2000; Hopwood, Shenton, Lalloo, Evans and Howell, 2001).

This is the first study to have attempted to measure and examine the impact of illness perceptions in a sample at increased risk of cancer. Although a number of subscales of the IPQ-R showed good internal reliability, for some this was not adequate. One subscale in particular (timeline cyclical) was removed from the analysis due to low internal reliability. This subscale was designed to assess perceptions of constancy in rapidly changing illnesses such as menstrual disorders (Moss-Morris et al., 2002). This concept may not be relevant to the timeframe of breast cancer. Beliefs regarding longer term issues such as recurrence are needed to capture this construct in this context. The identity, consequences and timeline acute/chronic subscales also showed only moderate internal consistency and may benefit from further refinement in this population. This may be best achieved by qualitative exploration of illness perceptions in ‘at risk populations’. This would provide a greater insight into the extent to which illness perceptions are developed and the relative importance of dimensions in this population as well as provide data with which to validate the use of the IPQ-R in this population.

Few differences in illness perceptions were identified between the groups. The finding that women at increased risk had a more coherent understanding of breast cancer and were more likely to agree that medically proven risk factors were causes of the disease than the comparison sample, suggest that genetic counselling may be effective in helping women to consolidate their representations of breast cancer and correctly identify the causes of the disease. However, there may be a number of factors that account for the differences between the samples, including difference in risk status, awareness of the risk and experience of breast cancer in the family. Further research is needed to clarify these issues, for example a controlled prospective study examining illness perceptions before and after genetic counselling.

Another limitation of the study that should be highlighted is that the sample was recruited from a single clinic and caution is needed to generalise findings. Both samples were predominately white, Caucasian and of high educational level as seen in other studies of screening populations (Kash et al., 1992; Codori, Hanson and Brandt, 1994; Rimer, Schildkraut, Lerman, Lin and Audrain, 1996). Individuals with a higher level of education are more likely to hold beliefs that are compatible with scientific and medical approaches (Bowling, 1989). The results of this study may not generalise to women of lower educational level or ethnic groups whose beliefs about breast cancer are likely to be diverse (Klonoff and Landrine, 1994). The poor response rate in the comparison sample was also problematic. This sample may have been biased towards women particularly interested in breast cancer and health issues. It is also possible that the samples were biased in terms of levels of distress. Women with high levels
of distress may avoid cues about their risk such as participating in research studies or even attending familial breast cancer clinics (Cull et al., 2001).

Although limited differences between illness perceptions were identified between the samples, what is interesting is that a number of illness perception subscales were associated with levels of distress in women at increased risk of breast cancer but not the comparison sample. The pattern of correlations in the increased risk sample replicates those found in patient samples including breast cancer patients (Weinman et al., 1996; Buick, 1997; Heijmans and De Ridder, 1998; Heijmans, 1999; Murphy et al., 1999; Scharloo et al., 2000). This may reflect the personal relevance of breast cancer representations when an individual is aware of their own genetic risk and indicates that the association between illness perceptions and distress may be moderated by an individual’s risk perception. However, the multiple regression analysis did not find any of the illness perception variables to be strong predictors of distress. It is possible that inter-correlations between the subscales may have created problems of collinearity in the multiple regression. This problem could be reduced by further refinement of measures in this population. Previous research using measures of illness perceptions showing high levels of reliability has found a range of cognitive perceptions to significantly predict emotional response to illness (e.g. Jopson and Moss-Morris, 2003). The results of this study provide tentative evidence that both illness perceptions and risk perception contribute independently to different aspects of psychological well-being in individuals at risk of disease. Research investigating psychological response to risk will benefit from further examination of the meaning of risk in terms of illness perceptions and refinement of measures, as well as investigating the interrelations between risk perception and illness perceptions.

The findings support the notion that identity is an important component of illness representations for healthy individuals (Bishop, Briede, Cavazos, Grotzinger and McMahon, 1987). Bishop et al. (1987) proposed that lay conceptions of illness are based primarily around symptoms in order to aid detection of disease. However, the symptoms outlined in the identity subscale were mainly generic and raise the problem that high scores on this and other measures may reflect a response bias. Although this study was based on the premise that illness perceptions influence adjustment to risk, the cross sectional nature of this study and many others in the literature mean that a number of alternative interpretations can be provided for the correlational patterns discovered. For example, negative affect may influence both levels of distress and illness perceptions. Individuals showing greater negative affect may be more prone to developing negative views of breast cancer. This is an area that needs to be examined. Causal relations are difficult to establish, although a few longitudinal studies have suggested that cognitive representations precede illness outcomes (Petrie et al., 1996; Orbell, Johnston, Rowley, Espley and Davy, 1998; Schiaffino, Shawaryn and Blum, 1998; Scharloo et al., 2000). Further intervention studies influencing cognitions are needed to provide causal evidence (e.g. Petrie, Cameron, Ellis, Buick and Weinman, 2002).

It was surprising that perceptions of control of breast cancer were not associated with distress in the increased risk sample since perceptions of control are found to be one of the most important determinants of adaptation in patient samples (Scharloo and Kaptein, 1997). Negative associations between beliefs over control of breast cancer and distress have been shown in breast cancer patients (Taylor et al., 1984; Buick, 1997). In addition, Cull et al. (2001) identified that low internal locus of control was associated with case level distress in women attending a familial ovarian cancer
clinic. However, the control subscales of the IPQ-R reflect perceptions of control over the prognosis and the recovery of disease. It is likely that different control perceptions are more relevant to this population, such as beliefs about control of risk, prevention of breast cancer and efficacy of detection methods. Audrain et al. (1997) used a single item to assess beliefs about control over developing breast cancer in women attending genetic counselling. Women who were categorised as having at least moderate perceived control over developing breast cancer, were found to show lower levels of general and cancer specific distress than those with no, or little, perceived control. The meaning of control in this population needs to be explored and examined in more detail.

In common with many studies guided by the SRM, this study focused on the cognitive representations component of the model. Further research is needed to investigate the coping and appraisal elements and interactions between these constructs. Research on coping in women at increased risk of breast cancer has tended to focus on the coping style rather than the coping strategies. Although qualitative studies have investigated how women cope with an increased risk of breast cancer, no specific measures are currently available (Appleton et al., 2000). Further research is required to investigate and assess specific coping strategies in this population, as well as satisfaction and appraisal of these strategies. Given the need to explore in greater detail of the type of illness perceptions formed by women at increased risk of breast cancer, qualitative studies exploring illness perceptions, coping and adjustment to risk in women at increased risk of breast cancer are required.

This study was guided by the SRM because the model was felt to examine in detail the meaning of risk for the individual. However, since the SRM was designed to primarily understand a patient’s response to illness, constructs reflecting perceived risk have not been explicitly incorporated into the model. It would be useful to determine how to incorporate beliefs about risk into the model. In order to achieve this, further research is required to examine the interactions between risk perception, illness perceptions, coping, appraisal and the psychological response to risk.

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References


