



Beliefs about medicine and illness are associated with fear of cancer recurrence in women taking adjuvant endocrine therapy for breast cancer

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Objectives. Adjuvant endocrine therapy for early-stage breast cancer has greatly reduced the morbidity and mortality associated with breast cancer recurrence. Despite this, a significant proportion of women report fears of cancer recurrence. This study examined the associations between fear of cancer recurrence (FoR) and illness perceptions, medication beliefs, and treatment side effects in women taking adjuvant endocrine therapy following breast cancer.

Methods. A total of 153 post-menopausal women with early-stage breast cancer completed a postal survey. Analyses were conducted to examine the association between FoR and illness perceptions, medication beliefs, treatment side effects, demographic factors, and emotional distress and to identify which of these factors would be most strongly associated with FoR in a regression model.

Results. All illness perceptions (apart from personal control) were associated with FoR, as were patient beliefs about endocrine therapy. Although treatment side effects, being unemployed, and higher levels of anxiety and depression were associated with FoR, only illness perceptions (identity, treatment control, timeline, and emotional representation) and medication necessity beliefs were significantly correlated with FoR in the final model.

Conclusions. It appears that, in addition to directly targeting FoR, it may be worthwhile to address the illness and medication beliefs supporting the fear. Additionally, helping women to differentiate everyday symptoms from those indicative of breast cancer may help to reduce fear of recurrence.

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Statement of Contribution

What is already known on this subject? A significant proportion of women report fear of cancer recurrence following breast cancer. The literature shows that illness perceptions, side effects of treatment, and beliefs about medicines are related to fear of recurrence among cancer patients. However, because these variables have often been looked at in isolation, it is not clear whether some perceptions or cues are more likely to relate to fear of recurrence than others.

What does this study add? This study shows illness perceptions and medication beliefs are strongly related to fears of cancer recurrence. The results point to ways in which the self-regulatory model of illness may be used to reduce patients' fear of recurrence. The study results show that women with higher fear of recurrence may be balancing a tension between believing that they need to take the medication to protect their future health alongside concerns that the treatment may not be working.

Globally, breast cancer is the most common cancer with an annual incidence of almost 1.4 million women (IARC, 2008). Between 75–80% of cases are classified as hormone receptor positive (Dowsett *et al.*, 2010), and adjuvant endocrine therapy with either tamoxifen or an aromatase inhibitor (AI) is typically prescribed for a period of 5 years or more with the aim of preventing recurrence (Myrick, Schid, Kilic & Guth, 2011). Targeted treatments and earlier detection mean that more women are living into the survivorship stages of care (DeSantis, Siegel, Bandi & Jemal, 2011). Despite these improvements, approximately half of patients diagnosed with breast cancer report significant fear of cancer recurrence (FoR) (van den Beuken-van Everdingen *et al.*, 2008; Deimling, Bowman, Sterns, Wagner & Kahana, 2006).

Fear of recurrence may persist for years after successful treatment (Northouse, 1981; Polinsky, 1994) and is associated with excessive checking for signs of cancer (Lee-Jones, Humphris, Dixon & Hatcher, 1997), mistaking benign symptoms as evidence of cancer, and more frequent contact with physicians for reassurance about new symptoms (Benyamini, McClain, Leventhal & Leventhal, 2003). Fear of recurrence is also related to poorer psychological adjustment and lower quality of life (Simard & Savard, 2009; Stanton, Danoff-Burg & Huggins, 2002), as well as intrusive thinking and avoidance of activities that evoke thoughts about breast cancer (Mehnert, Berg, Henrich & Herschbach, 2009).

Research with patients who have various types of cancer has shown that higher FoR is associated with demographic characteristics such as being younger (Wade, Nehmy & Koczwara, 2005), unemployed (Mehnert *et al.*, 2009), and female (Simard & Savard, 2009). Findings for the contribution of prognostic and medical variables to FoR are more mixed (e.g., Carver *et al.*, 2005; Deimling *et al.*, 2006; Mellon, Kershaw, Northouse & Freeman-Gibb, 2007), although it appears that more severe treatments such as chemotherapy and its lingering side effects are associated with increased fear (Lasry & Margolese, 1992; Mehnert *et al.*, 2009).

Recently, researchers have applied Leventhal's self-regulatory model of illness (SRM) as a framework for examining individual differences in FoR (Lee-Jones *et al.*, 1997). Central to the model is the notion that patients' illness beliefs guide coping behaviour, both in response to health threats such as new physical symptoms and to emotional responses to these threats (Leventhal, Diefenbach & Leventhal, 1992). The model

proposes that patients form beliefs about their illness along five dimensions: why they developed the illness (cause); the disease label and symptoms they associate with the condition (identity); how the illness is cured or controlled (control); how long the illness will last (timeline); and the everyday effects of the illness on the patient's life (consequences) (Petrie & Weinman, 2012). Research has shown that patients' views of their illness vary widely along these dimensions, even in patients with similar illnesses but are associated with important outcomes. For example, illness perceptions have been shown to predict psychological distress in women diagnosed with breast cancer 6 months after diagnosis (McCorry *et al.*, 2012) and are associated with distress, functioning, and even survival in other patient populations (Chilcot, Wellsted & Farrington, 2011; Dickens *et al.*, 2008; Kaptein *et al.*, 2010).

Research to date supports the relation between illness perceptions and FoR. For example, perceptions of longer illness timelines are related to higher FoR 3 months after chemotherapy among women with breast cancer (Rabin, Leventhal & Goodin, 2004). Stronger beliefs about personal control over breast cancer are related to fewer worries about whether cancer has been cured (Henselmans *et al.*, 2010). Additionally, greater beliefs in the consequences and emotional impact of the illness are related to higher FoR among patients diagnosed with head and neck cancer (Llewellyn, Weinman, McGurk & Humphris, 2008). A link between beliefs about illness identity and FoR has also been reported in one qualitative study on patients with gynaecological cancer (Bradley, Calvert, Pitts & Redman, 2001). Finally, there is some mixed evidence that beliefs about cancer cause are related to FoR and psychological adjustment post-breast cancer diagnosis (e.g., Lowery, Jacobsen & Ducette, 1993).

In addition to illness beliefs, the SRM has been extended to include patients' beliefs about their medications, such as the necessity of prescribed medication and its potential negative effects (Horne, Weinman & Hankins, 1999). Medication beliefs can shape coping behaviours via medication adherence and may also influence patients' experience of treatment side effects via negative expectancies (Barsky, Saintfort, Rogers & Borus, 2002; Bickell, Weidmann, Fei, Lin & Leventhal, 2009). Although a necessity-concerns framework has not yet been applied to the study of FoR, there is some evidence that uncertainty about treatment effectiveness is related to higher FoR (Marks, Richardson, Graham & Levine, 1986; Wong & Bramwell, 1992).

Applied to FoR, the SRM also suggests that internal cues such as physical symptoms can trigger FoR as patients search for the cause of their symptoms (Hagger & Orbell, 2003). For example, uncertainty about late emerging treatment side effects has been identified as a trigger of FoR (Easterling & Leventhal, 1989), and pain has been found to trigger FoR in women who have undergone breast cancer treatment (van den Beuken-van Everdingen *et al.*, 2008). Only one study has examined the relation between symptoms and FoR in women taking adjuvant endocrine therapy for breast cancer. It found that women taking tamoxifen who were higher in anxiety reported more treatment-related symptoms and greater cancer worry (Cameron, Leventhal & Love, 1998).

Overall, the existing literature suggests that illness perceptions, side effects of treatment, and beliefs about medicines are related to FoR among cancer patients. However, because these variables have often been looked at in isolation, it is not clear whether some perceptions or cues are more likely to relate to FoR than others. Additionally, the research has been conducted across many different cancer groups (e.g., haematological, gynaecological, breast, lung, & testicular cancer) with different prognoses for survival and cure rates. Furthermore, some of the research has focused on constructs such as worry about cancer cure rather than FoR. Finally, the research has

focused largely on cancer patients who have received surgery for cancer or who are undergoing chemotherapy or radiotherapy. It is not clear from the current literature how FoR relates to illness and medication beliefs and treatment side effects in women taking AIs as adjuvant endocrine therapy. This is an important area of research because of the distress associated with FoR, the increasing prevalence of early-stage hormone receptor-positive breast cancer, the growing numbers of women who are being prescribed adjuvant endocrine therapy for 5–10 years, and because of the strong association between reported side effects of adjuvant endocrine therapy and non-adherence to treatment (Cella & Fallowfield, 2008; Henry, Giles & Stearns, 2008; Pellegrini *et al.*, 2009).

Given this background, this study examined FoR and its relation to beliefs about breast cancer and treatment and reported side effects of AIs. Based on the SRM and existing research, it was predicted that illness perceptions, including longer disease timeline, greater perceived consequences, lower coherence beliefs, stronger emotional reactions to breast cancer, lower perceived control of breast cancer recurrence, and lower beliefs about the extent to which treatment with AIs could prevent cancer recurrence, would be related to increased FoR. Additionally, it was hypothesized that medication beliefs including higher beliefs in the necessity of medication and greater concerns about the medication would be related to higher FoR. Finally, it was hypothesized that more frequent and severe symptoms related to current use of AIs, as well as perceived symptoms from breast cancer, would be related to increased FoR. A secondary aim of this study was to identify which of these factors would be most strongly related to FoR, while controlling for other known correlates of FoR (e.g., anxiety and age).

Method

Participants and procedure

Following ethical approval from relevant district health boards and the Northern X Regional Ethics Committee, medical oncologists identified potential participants through a clinic records search. Women were eligible for the study if they were post-menopausal, had no history of breast cancer before being diagnosed with early-stage hormone receptor-positive breast cancer, and were undergoing adjuvant endocrine therapy with AIs. A total of 273 eligible women attending clinics within the medical oncology service throughout greater Auckland were identified, and all were invited to participate. They were sent an introductory letter, an anonymous postal survey, and reply-paid envelope, followed by a reminder letter 1 month after initial mail out. One hundred and fifty-nine women responded to the cross-sectional survey. Of these, six reported that they had stopped taking their AIs and were excluded from the sample. The final sample included 153 respondents (56% response rate).

Measures

Demographic and clinical variables

Patient-reported demographic variables included age, relationship status, income, employment status, and ethnicity. Patient-reported clinical variables included time since diagnosis, type of AI, previous adjuvant endocrine treatment, time on AI, total time on adjuvant endocrine therapy, and past treatment with surgery, chemotherapy, and/or radiotherapy.

Fear of cancer recurrence

Four items from the *Worry about Cancer Scale* (Easterling & Leventhal, 1989) assessed women's FoR. The scale or components of it have been used successfully to measure FoR in breast cancer survivors and in patients with head and neck cancer (Easterling & Leventhal, 1989; Llewellyn *et al.*, 2008). In this study, women rated their likelihood of experiencing cancer recurrence, the frequency with which they thought about recurrence, the extent to which thoughts of recurrence overflowed into daily activities, and the extent to which thoughts about recurrence were emotionally distressing. All four items were scored on 10-point Likert scales and were summed for a total FoR score ($\alpha = .81$).

Anxiety and depression

The *Hospital Anxiety and Depression Scale (HADS)* (Zigmond & Snaith, 1983) is a reliable and valid 14-item scale designed to assess anxiety and depression in populations with medical illness (Moorey *et al.*, 1991). Participants were asked to rate statements about how they were feeling during the last week on a 4-point Likert scale. The depression and anxiety items are summed to provide separate subscale scores, which range from 0 to 21 for each subscale. Cronbach's α was .85 for both subscales.

Beliefs about illness and treatment

The *Brief Illness Perception Questionnaire (BIPQ)* (Broadbent, Petrie, Main & Weinman, 2006) assessed women's perceptions of their breast cancer diagnosis along dimensions of illness identity, timeline, coherence, concern, treatment control, personal control, emotional representation, and consequences. For the purposes of the current study, we replaced the word illness with 'breast cancer diagnosis' (e.g., 'How much does your breast cancer diagnosis affect your life?'). Each dimension was rated on an 11-point Likert scale and analysed separately. Research indicates that the BIPQ is a reliable and valid measure of illness perceptions across a range of patient groups (Giri, Poole, Nightingale & Robertson, 2009; Lanteri-Minet *et al.*, 2007). To assess causal beliefs, participants were asked to identify three of the most likely causes of their breast cancer. The six most frequently endorsed causal categories (e.g., 'stress', 'genetics') were analysed for their association with FoR.

The *Beliefs about Medicines Questionnaire (BMQ)* (Horne & Weinman, 1999). The BMQ-specific was adapted in the current study to focus on women's beliefs about AIs. The BMQ contains 10 items that measure respondents' concerns about their medication and beliefs about the necessity of taking their medication. Respondents rate their agreement with each statement on a 5-point scale, and individual scale items are summed to create total 'concerns' ($\alpha = .84$) and 'necessities' ($\alpha = .86$) scores. The BMQ has been tested in a wide variety of patient populations and is a valid and reliable measure of medication beliefs (Horne & Weinman, 1999).

Treatment side effects

Side effects of AIs were measured using a scale adapted from Zivian and Salgado (2008). Women were asked to indicate whether they experienced each of 16 common side effects of AIs (e.g., hot flashes, fatigue, joint pain) on a 4-point scale ranging from 0 ('no side effect') to 3 ('severe side effect'). The severity ratings for each side effect were summed to create a total side effect severity score. Additionally, the total number of side effects women reported was counted.

Statistical analyses

Independent *t*-tests and analysis of variance (ANOVA) were used to assess group differences in demographic and treatment variables (e.g., ethnicity, medication type) on FoR scores. Spearman's correlation coefficients were calculated to assess the degree of relation between FoR and other measures such as participants' illness perceptions and beliefs about medicines. Multiple linear regression (simultaneous entry) was used to identify those variables most strongly associated with FoR. Only variables significantly correlated with FoR in univariate analyses were entered into the model due to sample size considerations.

Results

The majority of participants identified as NZ European (78.4%) and were evenly split between participants aged 45–60 years (50%) and those 61 years and older (50%). Most were married (68%) and just over half were employed (57%). The majority had undergone surgery (94%) and radiotherapy (79%), and over half received chemotherapy (60%). Of the three types of AIs, 57% were taking Femara, 41% Arimidex, and only 2% took Exemestane. Mean length of time on an AI was 2.3 years ($SD = 1.5$), and total time on any endocrine therapy including tamoxifen was 3.5 years ($SD = 2.4$). Time since diagnosis averaged 3.3 years ($SD = 1.6$).

There were no differences in FoR between younger ($M = 14.4$, $SD = 7.5$) and older ($M = 12.5$, $SD = 7.2$) participants ($t = 1.56$, $df = 148$, $p = .12$), nor were their differences between those who were single ($M = 13.6$, $SD = 7.9$) compared with those in a relationship ($M = 13.5$, $SD = 7.1$) ($t = 0.07$, $df = 149$, $p = .95$). Māori/Pacific participants reported higher mean FoR scores ($M = 17.1$, $SD = 9.3$) than NZ European respondents ($M = 13.1$, $SD = 7.1$) and those of 'Other' ethnicity ($M = 13.7$, $SD = 8.0$). However, these differences were non-significant ($F(2,148) = 1.32$, $p = .27$). There was a significant difference in FoR scores between unemployed participants ($M = 15.1$, $SD = 8.6$) and employed participants ($M = 12.9$, $SD = 6.2$) ($t = 2.25$, $df = 107$, $p = .03$, $d = .39$).

There were no significant associations between FoR and any of the treatment variables assessed. Fear of recurrence was not significantly correlated with time since breast cancer diagnosis ($r_s = -.15$, $p = .07$), length of time on an AI ($r_s = -.11$, $p = .21$), or total time on adjuvant endocrine therapy, including previous use of tamoxifen ($r_s = -.06$, $p = .44$). Fear of recurrence scores were equivalent between women who had undergone chemotherapy ($M = 13.8$, $SD = 7.4$) and women who had not ($M = 13.3$, $SD = 7.5$). Similarly, there were no significant differences in FoR between those who had undergone radiotherapy ($M = 13.5$, $SD = 7.2$) and those who had not ($M = 13.6$, $SD = 8.5$) ($t = -0.52$, $df = 145$, $p = .96$). Finally, FoR did not differ significantly by type of AI as women taking Arimidex ($M = 14.6$, $SD = 8.2$) did not have significantly higher FoR scores than women taking Femara ($M = 12.7$, $SD = 6.8$) ($t = -1.46$, $df = 114$, $p = .15$). There were significant correlations between mean anxiety and depression scores and FoR (Table 1).

Fear of recurrence was significantly related to all dimensions of illness perceptions apart from personal control over cancer recurrence (Table 1). Specifically, higher FoR was associated with beliefs in higher consequences of breast cancer, a longer disease timeline, greater concerns and more negative emotions associated with the diagnosis, more symptoms associated with breast cancer, as well as lower coherence and treatment control beliefs. Results also showed that women who identified stress as the cause of their

Table 1. Mean scores and SD for illness and medication beliefs, the HADS, treatment side effects, and correlation with fear of recurrence

Measure	Dimension	Mean (SD)	Correlation with fear of recurrence (r_s)
Fear of recurrence		13.5 (7.4)	1.00
Illness beliefs	Emotion	3.5 (3.0)	.60**
	Consequences	3.4 (2.9)	.59**
	Timeline	5.8 (3.8)	.53**
	Concerns	4.5 (3.3)	.52**
	Identity	2.7 (2.8)	.48**
	Coherence	7.9 (2.5)	-.27**
	Treatment control	6.9 (2.5)	-.20*
	Personal control	4.1 (3.3)	-.14
Beliefs about medicine	Concerns	11.6 (4.1)	.35**
	Necessity	13.7 (4.5)	.27**
Side effects	Severity	14.0 (9.6)	.34**
	Number	7.7 (4.1)	.31**
HADS	Depression	2.0 (4.0) ¹	.54**
	Anxiety	5.0 (6.0) ¹	.44**

Note. ¹For HADS anxiety and depression scores, median range and interquartile range are shown. * $p = .05$ level; ** $p = .001$ level (2-tailed tests).

cancer reported higher FoR, whereas women who indicated that they did not know what caused their cancer reported significantly lower FoR (Table 2). There were no other significant differences in FoR scores across the causal categories.

Findings for participants' beliefs about medicines were significant for both subscales of the BMQ. Higher FoR scores were significantly associated with higher concerns about taking AIs, as well as greater beliefs in the necessity of taking AIs (Table 1).

Table 2. Differences in fear of recurrence scores based on beliefs about cancer cause

Cause	Response (n)	M (SD)	Mean difference	95% Confidence interval		<i>d</i>
				Lower	Upper	
Do not know	No (120)	14.3 (7.47)	4.0**	0.93	7.16	.43
	Yes (27)	10.3 (6.30)				
Stress	No (92)	12.6 (6.57)	-2.7*	-5.19	-0.22	.36
	Yes (55)	15.2 (8.47)				
Lifestyle	No (99)	12.9 (7.22)	-2.1	0.93	7.16	.27
	Yes (45)	15.0 (7.66)				
Hormones	No (112)	14.0 (7.65)	1.6	-1.76	4.92	.16
	Yes (33)	12.3 (6.47)				
Genetics	No (104)	13.4 (7.67)	-0.7	-3.42	1.92	.09
	Yes (43)	14.1 (6.86)				
Chance	No (127)	13.6 (7.34)	0.3	-3.20	3.88	.03
	Yes (20)	13.3 (8.14)				

Note. * $p = .05$, ** $p = .01$ (two-tailed).

Table 3. Predicting fear of recurrence

Predictor variables	B	SE B	β	p-value
BIPQ: treatment control	-0.73	0.20	-0.24	.001
BIPQ: emotion	-0.75	0.22	0.32	.001
BIPQ: timeline	0.42	0.13	0.23	.002
BIPQ: identity	0.52	0.21	0.19	.015
BMQ: necessity	0.28	0.11	0.17	.016
BIPQ: consequences	0.30	0.24	0.12	.210
Employment status	0.96	0.89	0.07	.285
BIPQ: concerns	0.17	0.17	0.78	.315
Anxiety	0.17	0.20	0.09	.385
Depression	-0.14	0.18	-0.07	.435
Do not know cause	-0.92	1.22	-0.05	.454
BIPQ: coherence	-0.11	0.19	-0.04	.569
Stress cause	0.42	1.02	0.03	.682
BMQ: concerns	-0.05	0.13	-0.03	.718
Number of side effects	-0.11	0.31	-0.06	.720
Side effect severity	0.02	0.14	0.03	.862

Note. Overall Model: $R = .81$; $R^2 = .66$; Adjusted $R^2 = .61$; $F(16,102) = 12.23$, $p < .001$. Collinearity statistics of tolerance and variance inflation factors were within acceptable ranges (<0.1 and <10 , respectively).

Participants reported an average of eight side effects from their AIs ($M = 7.7$, $SD = 4.1$, range = 0–16). Analyses showed significant positive relations between FoR and participants' total side effect severity scores as well as the number of reported side effects from AIs (Table 1).

Illness perceptions and beliefs about medicines significantly associated with FoR were entered into a regression model as potential predictor variables, and anxiety, depression, and employment status were included as covariates (Table 3). Overall, the model accounted for 61% of the variance in FoR scores. Findings showed that illness perceptions, including lower beliefs about treatment control, more negative emotion associated with the diagnosis, longer timelines for the experience of breast cancer, and more symptoms attributed to breast cancer (identity) were significantly associated with FoR. Beliefs about medicines were also significant, with higher beliefs in the necessity of taking AIs associated with higher FoR. The size of the standardised beta coefficients indicates a small to moderate effect for each perception, with BIPQ treatment control beliefs having the largest unique effect. No other variables were significantly associated with FoR in the regression model.

Discussion

This study examined the relations between FoR and illness and medication beliefs, and treatment side effects among a sample of post-menopausal women taking AIs as adjuvant endocrine therapy for early-stage breast cancer. As hypothesized, all illness perceptions were significantly correlated with FoR in the predicted direction, except for personal control beliefs. Beliefs about medicines were also correlated with FoR, as were the number and severity of reported side effects of AIs. These variables along with covariates anxiety, depression, and participant employment status accounted for 61% of the variance

in FoR scores. However, only illness and medication beliefs were significantly associated with FoR in the regression model.

These findings replicate and extend previous research by showing that in addition to beliefs about illness timeline, consequences, emotion, identity, and cancer cause (Llewellyn *et al.*, 2008; Pederson, Rossen, Olesen, von der Maase & Vedsted, 2011; Rabin *et al.*, 2004), coherence and treatment control beliefs are also significantly related to FoR among women taking AIs. The results of this study also suggest that some illness perceptions may be more strongly associated with FoR than others, as only negative emotions associated with the diagnosis, longer timeline, lower beliefs about treatment control, and greater symptoms attributed to breast cancer were significantly associated with FoR in the regression model.

The finding that more negative emotions associated with breast cancer diagnosis predict FoR is difficult to interpret given the cross-sectional nature of the study. Stronger emotional responses to the diagnosis at the time of sampling may amplify FoR, or vice versa. Prospective research would clarify these effects. However, one study found that emotion beliefs did not predict FoR over time among patients with head and neck cancer (Llewellyn *et al.*, 2008). The finding from the present study that longer illness timeline predicts FoR replicates a previous finding (Rabin *et al.*, 2004), but further clarity on what this actually means for women is needed. For example, it may be that some women believe that their cancer has not been cured and that there are cancer cells still in their body, whereas other women may believe that they are cured but at greater risk of recurrence because of prognostic or genetic factors. If these were true, interventions may need to be tailored to target differences in underlying beliefs.

The SRM suggests that patients use illness beliefs to guide a search to identify the cause of their physical symptoms, which will affect FoR. Findings from this study tentatively support this idea, as higher reports of symptoms from breast cancer (illness identity) were significantly associated with higher FoR. This finding is interesting in that breast cancer itself does not have any symptoms once the tumour has been removed, and it is not clear from the current research, what sorts of symptoms women were attributing to the breast cancer. It may be that pain or tightness from surgical scars triggers thoughts of breast cancer that in turn contribute to FoR. This possibility requires testing in future research.

This study also found that causal beliefs were significantly related to FoR; women who attributed the cause of cancer to stress also reported higher FoR scores. Similar findings come from studies of patients with testicular cancer (Pederson *et al.*, 2011) and of patients with gynaecological cancer (Costanzo, Lutgendorf, Bradely, Rose & Anderson, 2005), and it has been suggested that attributing cancer to psychological causes contributes to increased distress (Kulik & Kronfeld, 2005). Interestingly, the current study also found that women who reported that they 'do not know' what caused their cancer had significantly lower FoR scores. This novel finding may mean that women who are less fearful of a cancer recurrence are also less likely to search for and identify 'causes' of their illness. Alternatively, it is possible that women who indicate that they 'do not know' what caused their cancer are better at managing the uncertainty associated with their diagnosis. Despite significant associations with FoR, causal beliefs were not significantly related to FoR in the regression model.

This study also showed that medication beliefs were linked to FoR. Higher concerns about AIs, as well as higher beliefs in the necessity of taking AIs, were significantly associated with FoR, but only the latter predicted FoR in the regression model. This finding is notable because at the same time, FoR was found to be negatively related to the treatment control dimension of the BIPQ. These findings seem to suggest that although

women who are higher in FoR believe more strongly in the necessity of taking AIs to protect their future health, they are less likely to believe that AIs will protect them against cancer recurrence. It has been suggested that uncertainty about treatment effectiveness may contribute to FoR in women who have had a mastectomy (Wong & Bramwell, 1992). However, the current study is the first to show that women taking AIs may have conflicting feelings about the necessity of treatment and its ability to control cancer.

In this study, women reported an average of eight symptoms from their AIs. However, side effects of medication were not significantly associated with FoR in the regression model. Instead, beliefs about illness 'identity' or symptoms attributed to breast cancer were predictive of FoR. Previous research has linked side effects of surgery, chemotherapy, and radiotherapy to FoR (Benyamini *et al.*, 2003; van den Beuken-van Everdingen *et al.*, 2008; Deimling *et al.*, 2006; Easterling & Leventhal, 1989; Kiebert, Welvaart & Kievit, 1993), and it has been suggested that side effects of treatment might be viewed as a constant reminder or indicator of cancer (Gil *et al.*, 2004; Gray *et al.*, 1998; Skaali *et al.*, 2009). However, the current findings suggest that it may be the attribution for the source of the symptoms that triggers FoR. Women who attribute their symptoms to the medication and who view symptoms as a sign that the medication is working may feel less fearful even though they are experiencing similar physical triggers as women who attribute symptoms to breast cancer. Future research on symptom attribution in this population is needed, as well as research to identify whether certain symptoms are more likely to trigger FoR than others.

As noted previously, the cross-sectional design of this study is a limitation that precludes causal interpretation of the relations among FoR, illness and medication beliefs, and treatment side effects. A prospective design would be needed to assess whether illness and medication beliefs emerge as casual factors in FoR over time. Nevertheless, time since diagnosis was not related to FoR in this study, making the possibility that the passage of time would change the relation of FoR to medication and illness perceptions less likely. A further limitation is the generalizability of the findings given that the study sample was comprised of mainly New Zealand European women who were attending follow-up oncology clinics and who responded to the postal survey. Finally, clinical data on actual risk of recurrence were not assessed nor were data on the severity of cancer diagnoses. It may be that women reporting higher FoR actually had more severe diagnoses and worse prognoses. However, previous research has shown that illness perceptions are more predictive of FoR than clinical markers of disease (Mellon *et al.*, 2007) and that actual prognosis regarding risk of recurrence is unrelated to women's perceptions of risk (Liu *et al.*, 2010). Furthermore, women's reported treatment history, which may be considered a marker of disease severity, was unrelated to FoR in this study.

Conclusions

Mortality rates from breast cancer are decreasing (DeSantis *et al.*, 2011), and the likelihood of disease-free survival increases with adjuvant endocrine therapy with AIs (Dowsett *et al.*, 2010; Petit, Dufour & Tannock, 2011). Indeed, this treatment is often described as an insurance policy against a possible recurrence. Despite this, FoR is common among women taking adjuvant endocrine therapy.

The results of this study provide additional support for application of the SRM to understanding factors that influence FoR and show that illness and medication beliefs are significant predictors of FoR over and above factors such as employment status and mood. Importantly, the results show that women with higher FoR may be balancing the belief

that they need to take the medication to protect their future health alongside concerns that the treatment may not be working. Additionally, findings suggest that women who attribute the physical symptoms they are experiencing to breast cancer are more likely to experience FoR. There is evidence that patients want help to manage FoR (Armes *et al.*, 2009; Thewes *et al.*, 2011), and it may be that in addition to tackling the fear itself, changing maladaptive illness and medication beliefs that fuel the fear would be an appropriate target for intervention. Recent studies among other patient populations have demonstrated that interventions based on illness perceptions have positive effects on patient outcomes, and these could potentially be applied to women taking AIs (Broadbent, Ellis, Thomas, Gamble & Petrie, 2009; Keogh *et al.*, 2011; Petrie, Perry, Broadbent & Weinman, 2011).

References

- Armes, J., Crowe, M., Colbourne, L., Morgan, H., Murrells, T., Oakley, C., ... Richardson, A. (2009). Patient's supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *Journal of Clinical Oncology*, *27*, 6172–6179. doi:10.1200/JCO.2009.22.5151
- Barsky, A. J., Saintfort, R., Rogers, M. P., & Borus, J. F. (2002). Nonspecific medication side effects and the nocebo phenomenon. *Journal of the American Medical Association*, *287*, 622–627. doi:10.1001/jama.287.5.622
- Benyamini, Y., McClain, C. S., Leventhal, E. A., & Leventhal, H. (2003). Living with the worry of cancer: health perceptions and behaviors of elderly people with self, vicarious, or no history of cancer. *Psycho-Oncology*, *12*, 161–172. doi:10.1002/pon.637
- Bickell, N. A., Weidmann, J., Fei, K., Lin, J. J., & Leventhal, H. (2009). Underuse of breast cancer adjuvant treatment: patient knowledge, beliefs, and medical mistrust. *Journal of Clinical Oncology*, *27*, 5160–5167. doi:10.1200/JCO.2009.22.9773
- Bradley, E. J., Calvert, E., Pitts, M. K., & Redman, C. W. E. (2001). Illness identity and the self-regulatory model in recovery from early stage gynaecological cancer. *Journal of Health Psychology*, *6*, 511–521. doi:10.1177/135910530100600505
- Broadbent, E., Ellis, C. J., Thomas, J., Gamble, G., & Petrie, K. J. (2009). Further development of an illness perception intervention for myocardial infarction patients: A randomized trial. *Journal of Psychosomatic Research*, *67*, 17–23. doi:10.1016/j.jpsychores.2008.12.001
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The brief illness perceptions questionnaire. *Journal of Psychosomatic Research*, *60*, 631–637. doi:10.1016/jpsychores.2005.10.020
- Cameron, L. D., Leventhal, H., & Love, R. R. (1998). Trait anxiety, symptoms perceptions, and illness-related responses among women with breast cancer in remission during a tamoxifen clinical trial. *Health Psychology*, *17*, 459–469. doi:10.1037/0278-6133.17.5.459
- Carver, C. S., Smith, R. G., Antoni, M. H., Petronis, V. M., Weiss, S., & Derhagopian, R. P. (2005). Optimistic personality and psychosocial well-being during treatment predict psychosocial well-being among long-term survivors of breast cancer. *Health Psychology*, *24*, 508–516. doi:10.1037/0278-6133.24.5.508
- Cella, D., & Fallowfield, L. J. (2008). Recognition and management of treatment-related side effects for breast cancer patients receiving adjuvant endocrine therapy. *Breast Cancer Research and Treatment*, *107*, 167–180. doi:10.1007/s10549-007-9548-1
- Chilcot, J., Wellsted, D., & Farrington, K. (2011). Illness perceptions predict survival in haemodialysis patients. *American Journal of Nephrology*, *33*, 358–363. doi:10.1159/000326752
- Costanzo, E. S., Lutgendorf, S. D., Bradely, B. C., Rose, S. L., & Anderson, B. (2005). Cancer attributions, distress, and health practices among gynecologic cancer survivors. *Psychosomatic Medicine*, *67*, 972–980. doi:10.1097/01.psy.0000188402.95398.c0

- Deimling, G. T., Bowman, K. F., Sterns, S., Wagner, L. J., & Kahana, B. (2006). Cancer-related health worries and psychological distress among older adult, long-term cancer survivors. *Psycho-Oncology*, *15*, 306–320. doi:10.1002/pon.955
- DeSantis, C., Siegel, R., Bandi, P., & Jemal, A. (2011). Breast cancer Statistics, 2011. *CA: A Cancer Journal for Clinicians*, *61*, 409–418. doi:10.3322/caac.20134
- Dickens, C., McGowan, L., Percival, C., Tomenson, B., Cotter, L., Heagerty, A., & Creed, F. (2008). Negative illness perceptions are associated with new-onset depression following myocardial infarction. *General Hospital Psychiatry*, *30*, 414–420. doi:10.1016/j.genhosppsy.2008.04.003
- Dowsett, M., Cuzick, J., Ingle, J., Coates, A., Forbes, J., & Bliss, J. (2010). Meta-analysis of breast cancer outcomes in adjuvant trials of aromatase inhibitors versus tamoxifen. *Journal of Clinical Oncology*, *28*, 509–518. doi:10.1200/JCO.2009.23.1274
- Easterling, D. V., & Leventhal, H. (1989). Contribution of concrete cognition to emotion: neutral symptoms as elicitors of worry about cancer. *Journal of Applied Psychology*, *74*, 787–796. doi:10.1037/0021-9010.74.5.787
- Gil, K. M., Mishel, M., Belyea, M., Bermino, B., Germino, L. S., Porter, L., ... Stewart, J. (2004). Triggers of uncertainty about recurrence and long-term side effects in older African American and Caucasian breast cancer survivors. *Oncology Nursing Forum*, *31*, 633–639. doi:10.1188/04.onf.20633-639
- Giri, P., Poole, J., Nightingale, P., & Robertson, A. (2009). Perceptions of illness and their impact on sickness absence. *Occupational Medicine*, *59*, 550–555. doi:10.1093/occmed/kqp123
- Gray, R. E., Fitch, M., Greenberg, M., Hampson, A., Doherty, M., & Labrecque, M. (1998). The information needs of well, longer-term survivors of breast cancer. *Patient Education and Counseling*, *33*, 245–255. doi:10.1016/S0738-2991(98)00024-X
- Hagger, M. S., & Orbell, S. A. (2003). Meta-analytic review of the common-sense model of illness representations. *Psychology & Health*, *18*, 141–184. doi:10.1080/088704403100081321
- Henry, N. L., Giles, J. T., & Stearns, V. (2008). Aromatase inhibitor associated musculoskeletal symptoms: etiology and strategies for management. *Oncology*, *22*, 1–12. doi:10.1007/s10549-007-9774-6
- Henselmans, I., Sanderman, R., Helgeson, V. S., de Vries, J., Smink, A., & Ranchor, A. V. (2010). Personal control over the cure of breast cancer: adaptiveness, underlying beliefs and correlates. *Psycho-Oncology*, *19*, 525–534. doi:10.1002/pon.1599
- Horne, R., & Weinman, J. (1999). Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. *Journal of Psychosomatic Research*, *47*, 555–567. doi:10.1016/S0022-3999(99)00057-4
- Horne, R., Weinman, J., & Hankins, M. (1999). The beliefs about medicines questionnaire: the development and evaluation of a new method for assessing the cognitive representation of medication. *Psychology & Health*, *14*, 1–24. doi:10.1080/08870449908407311
- IARC (2008). Breast cancer incidence and mortality worldwide in 2008 summary. Globocan. Retrieved from: <http://globocan.iarc.fr/factsheets/cancers/breast.asp>
- Kaptein, A. A., Bijsterbosch, J., Scharloo, M., Hampson, S. E., Kroon, H. M., & Kloppenburg, M. (2010). Using the common sense model of illness perceptions to examine osteoarthritis change: a 6-year longitudinal study. *Health Psychology*, *29*, 56–64. doi:10.1037/a0017787
- Keogh, K. M., Smith, S. M., White, P., McGilloway, S., Kelly, A., Gibney, J., & O'Dowd, T. (2011). Psychological family intervention for poorly controlled type 2 diabetes. *American Journal of Managed Care*, *17*, 105–113.
- Kiebert, G. M., Welvaart, K., & Kievit, J. (1993). Psychological effects of routine follow up on cancer patients after surgery. *European Journal of Surgery*, *159*, 601–607.
- Kulik, L., & Kronfeld, M. (2005). Adjustment to breast cancer: contribution of resources and causal attributions regarding the illness. *Social Work in Health Care*, *41*, 37–57. doi:10.1300/J010v41n02_03
- Lanteri-Minet, M., Massiou, H., Nachit-Ouinekh, F., Lucas, C., Pradalier, A., Radat, F., ... El Hasnaoui, A. (2007). The GRIM2005 study of migraine consultation in France I. Determinants of

- consultation for migraine headache in France. *Cephalgia*, 27, 1386–1397. doi:10.1111/j.1468-2982.2007.01426.x
- Lasry, J. C. M., & Margoese, R. G. (1992). Fear of recurrence, breast-conserving surgery, and the trade-off hypothesis. *Cancer*, 69, 2111–2115. doi:10.1002/1097-0142
- Lee-Jones, C., Humphris, G., Dixon, R., & Hatcher, M. B. (1997). Fear of cancer recurrence – a literature review and proposed cognitive formulation to explain exacerbation of recurrence fears. *Psycho-Oncology*, 6, 95–105.
- Leventhal, H., Diefenbach, M., & Leventhal, E. A. (1992). Illness cognition: using common sense to understand treatment adherence, and affect cognition interactions. *Cognitive Therapy and Research*, 16, 143–163. doi:10.1007/BF01173486
- Liu, Y., Pérez, M., Aft, R. L., Massman, K., Robinson, E., Myles, S., & Schootman, M. (2010). Accuracy of perceived risk of recurrence among patients with early-stage breast cancer. *Cancer Epidemiology, Biomarkers & Prevention*, 19, 675–680. doi:10.1158/1055-9965.EPI-09-1051
- Llewellyn, C. D., Weinman, J., McGurk, M., & Humphris, G. (2008). Can we predict which head and neck cancer survivors develop fears of recurrence? *Journal of Psychosomatic Research*, 65, 525–532. doi:10.1016/j.jpsychores.2008.03.014
- Lowery, B. J., Jacobsen, B. S., & Ducette, J. (1993). Causal attribution, control, and adjustment to breast cancer. *Journal of Psychosocial Oncology*, 10, 37–53. doi:10.1300/J077V10N04_03
- Marks, G., Richardson, J. L., Graham, J. W., & Levine, A. (1986). Role of health locus of control beliefs and expectations of treatment efficacy in adjustment to cancer. *Journal of Personality and Social Psychology*, 51, 443–450. doi:10.1037//0022-3514.51.2.443
- McCorry, N. K., Dempster, M., Quinn, J., Hogg, A., Newell, J., Moore, M., Kelly, S., & Kirk, S. J. (2012). Illness perception clusters at diagnosis predict psychological distress among women with breast cancer a 6 months post diagnosis. *Psycho-Oncology*. Advance online publication. doi: 10.1002/pon.3054
- Mehnert, A., Berg, P., Henrich, G., & Herschbach, P. (2009). Fear of cancer progression and cancer-related intrusive cognitions in breast cancer survivors. *Psycho-Oncology*, 18, 1273–1280. doi:10.1002/pon.1481
- Mellon, S., Kershaw, T. S., Northouse, L. L., & Freeman-Gibb, L. (2007). A family-based model to predict fear of recurrence for cancer survivors and their caregivers. *Psycho-Oncology*, 16, 214–223. doi:10.1002/pon.1074
- Moorey, S., Greer, S., Watson, M., Gorman, C., Rowden, L., Tunmore, R., Robertson, B., & Bliss, J. (1991). The factor structure and factor stability of the hospital anxiety and depression scale in patients with cancer. *British Journal of Psychiatry*, 158, 255–259. doi:10.1192/bjp.158.2.255
- Myrick, M. E., Schid, S. M., Kilic, N., & Guth, U. (2011). Eligibility, compliance and persistence of extended adjuvant endocrine therapy for breast cancer. *Acta Oncologica*, 51, 247–253. doi:10.1159/000330768
- Northouse, L. L. (1981). Mastectomy patients and the fear of cancer recurrence. *Cancer Nursing*, 6, 213–220. doi:10.1097/00002820-198106000-00004
- Pederson, A. F., Rossen, P., Olesen, F., von der Maase, H., & Vedsted, P. (2011). Fear of recurrence and causal attributions in long-term survivors of testicular cancer. *Psycho-Oncology*. Advance online publication. doi:10.1002/pon.2030
- Pellegrini, I., Sarradon-Eck, A., Soussan, P. B., Lacour, A.-C., Largillier, R., Tallet, A., ... Julian-Reynier, C. (2009). Women's perceptions and experience of adjuvant tamoxifen therapy account for their adherence: breast cancer patients' point of view. *Psycho-Oncology*, 19, 472–479. doi:10.1002/pon.1593
- Petit, T., Dufour, P., & Tannock, I. (2011). A critical evaluation of the role of aromatase inhibitors as adjuvant therapy for postmenopausal women with breast cancer. *Endocrine Related Cancer*, 18, 79–89. doi:10.1530/ERC-10-0162
- Petrie, K. J., Perry, K., Broadbent, E., & Weinman, J. (2011). A text message program designed to modify patients' illness and treatment beliefs improves self-reported adherence to asthma preventer medication. *British Journal of Health Psychology*, 17, 74–84. doi:10.1111/j.2044-8287.2011.02033.x

- Petrie, K. J., & Weinman, J. (2012). Patients' perceptions of their illness: The dynamo of volition in health care. *Current Directions in Psychological Science*, *21*, 60–65. doi:10.1177/0963721411429456
- Polinsky, M. L. (1994). Functional status of long-term breast cancer survivors: demonstrating chronicity. *Health and Social Work*, *19*, 165–173. doi:10.1093/hsw/19.3.165
- Rabin, C., Leventhal, H., & Goodin, S. (2004). Conceptualization of disease timeline predicts posttreatment distress in breast cancer patients. *Health Psychology*, *23*, 407–412. doi:10.1037/0278-6133.23.4.407
- Simard, S., & Savard, J. (2009). Fear of Cancer Recurrence Inventory: development and initial validation of a multidimensional measure of fear of cancer recurrence. *Supportive Care in Cancer*, *17*, 241–251. doi:10.1007/s00520-008-0444-y
- Skaali, T., Fosså, S. D., Bremnes, R., Dahl, O., Haaland, C. F., Hauge, E. R., ... Dahl, A.A. (2009). Fear of recurrence in long-term testicular cancer survivors. *Psycho-Oncology*, *18*, 580–588. doi:10.1002/pon.1437
- Stanton, A. L., Danoff-Burg, S., & Huggins, M. E. (2002). The first year after breast cancer diagnosis: hope and coping strategies as predictors of adjustment. *Psycho-Oncology*, *11*, 93–102. doi:10.1002/pon.574
- Thewes, B., Butow, P., Zachariae, R., Christensen, S., Simard, S., & Gotay, C. (2011). Fear of cancer recurrence: a systematic literature review of self-report measures. *Psycho-Oncology*, *21*, 571–581. doi: 10.1002/pon.2070
- van den Beuken-van Everdingen, M. H. J., Peters, M. L., de Rijke, J. M., Schouten, H. C., van Kleef, M., & Patijn, J. (2008). Concerns of former breast cancer patients about disease recurrence: a validation and prevalence study. *Psycho-Oncology*, *17*, 1137–1145. doi:10.1002/pon.1340
- Wade, T. D., Nehmy, T., & Koczwara, B. (2005). Predicting worries about health after breast cancer surgery. *Psycho-Oncology*, *14*, 503–509. doi:10.1002/pon.866
- Wong, C. A., & Bramwell, L. (1992). Uncertainty and anxiety after mastectomy for breast cancer. *Cancer Nursing*, *15*, 363–371. doi:10.1097/00002820-199210000-00006
- Zigmond, A. S., & Snaith, R. P. (1983). The Hospital and Anxiety Depression Scale. *Acta Psychiatrica Scandinavica*, *67*, 361–370. doi:10.1111/j.1600-0447.1983.tb09716.x
- Zivian, M. T., & Salgado, B. (2008). Side effects revisited: women's experiences with aromatase inhibitors. Breast Cancer Action. Retrieved from: <http://bcaction.org/wp-content/uploads/2011/03/AI-Report-June-2008-Final-ONLINE.pdf>

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