

The relationship between illness representations, risk perception and fear of cancer recurrence in breast cancer survivors

Short: Relationship of illness representation to fear of recurrence in cancer survivors

Laurie A. Freeman-Gibb, PhD (a)

Nancy K. Janz PhD (b)

Maria C. Katapodi (c)

Brian J. Zikmund-Fisher PhD (b)

Laurel Northouse PhD (d)

(a)University of Windsor,

(b) University of Michigan School of Public Health, (c) University of Basel Institute of Nursing Science/Faculty of Medicine (d) University of Michigan School of Nursing

Corresponding author: Laurie A. Freeman-Gibb, RN, PhD, A-NP.

University of Windsor- Faculty of Nursing

401 Sunset Ave, Windsor,

ON, CAN,

N8Y 3P4

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as doi: [10.1002/pon.4143](https://doi.org/10.1002/pon.4143)

[lgibb@uwindsor.ca](mailto:lgibb@uwindsor.ca)

Phone:(519) 253-3000 ext. 2278

Fax: (519) 973-7084

## ABSTRACT

**Objective:** Fear of cancer recurrence, although distinct from distress continues to be under-evaluated, captured, or treated when standard distress scales are used to assess concerns of cancer survivors. We tested a model assessing the association of *demographic and clinical factors*, illness representations, and perceived risk with fear of cancer recurrence in breast cancer survivors.

**Methods:** We recruited 117 breast cancer survivors at least one year after completing breast cancer treatment from Internet discussion boards for this cross-sectional, descriptive, correlational study. Participants completed a survey that assessed their level of fear of cancer recurrence as well as their illness representations, perceived risk of recurrence, demographic and medical characteristics.

**Results:** Our model explained 62% of the variance in fear of cancer recurrence. *Emotional representations* ( $\beta = .46, p < .01$ ), *symptom attribution* ( $\beta = .21, p < .01$ ), *timeline* ( $\beta = .23, p < .01$ ), and *consequences* ( $\beta = .16, p < .03$ ) were significantly related to fear of recurrence. By contrast, the majority of clinical and demographic variables were not significant contributors to fear of recurrence.

**Conclusions:** Upon completion of cancer treatment, survivors with more emotional representations of the experience and those who attribute unrelated symptoms to their breast cancer have a higher level of fear of recurrence. Evaluation of these factors during treatment may help mitigate fear of recurrence in the survivorship phase of the breast cancer trajectory.

**Key Words:** Cancer, Oncology, Internet Recruitment, Emotional representations, Symptom attribution, Breast cancer survivorship

## **BACKGROUND**

There are currently 2.8 million women alive in the United States who have survived a breast cancer diagnosis [1]. Breast cancer survivors are in need of follow-up care to assess ongoing psychological needs, evaluate latent physical effects of treatment, and monitor for breast cancer recurrence [2]. One of the greatest concerns of breast cancer survivors is fear of cancer recurrence (FOCR) [3-5].

FOCR is a universal ongoing concern that women with breast cancer face to varying degrees in their survivorship trajectory [6-11]. As early as the 1970's, researchers reported clinical observations of seemingly well-adjusted cancer survivors experiencing subclinical issues and distress long after their cancer had been treated and deemed in control [13-15]. The concept of FOCR emerged from these early studies and has increasingly been identified as different from anxiety, depression, posttraumatic stress disorder (PTSD) while also having a negative impact on quality of life in survivorship [4, 7, 8, 16-19]. Because it is a distinct concept, fear of recurrence is not evaluated, captured, or treated when standard distress scales are used to assess cancer survivors' concerns [8-10, 19-22].

Efforts to identify factors associated with higher FOCR in breast cancer survivors and other cancer survivors have only been partially successful. In general, past studies found that being younger, having children, coming from a

Illness representations, risk perception and fear of cancer recurrence

lower socioeconomic group and having less education were associated with more FOCR [3-5]. However, findings are mixed in regard to other demographic and clinical factors such as ethnicity, time since diagnosis and type of treatment. Factors such as anxiety, depression, and various triggers were related to FOCR in many studies, although the exact relationship and amount of contribution differed widely [3,4,19-22].

Examining illness representations in breast cancer patients may help explain which survivors have higher levels of FOCR. Illness representations are individuals' cognitive and emotional interpretations of an illness threat [23-25]. Individuals appraise an illness threat in order to determine if it is serious and needs attention versus a minor issue that will resolve on its own [23-25]. These appraisals determine the development of illness representations and shape future responses to illness threats along with dictating health behaviors [23-25].

Although research on illness representations within oncology has produced mixed results, due to different instruments used and endpoints assessed [26-29], some evidence indicates that illness representations may affect FOCR among cancer survivors [29]. Breast cancer patients with more of an emotional representation of their disease had a poorer perception of their overall physical and mental health [26]. Furthermore head and neck cancer patients with an illness representation of more severe consequences associated with their

Illness representations, risk perception and fear of cancer recurrence

cancer and who also held stronger emotional representations of their illness had greater FOQR [29]. No relationship was found between demographic or objective medical factors and patients' ongoing FOQR. These findings suggest that illness representations alone may be a key factor associated with fear of recurrence in cancer patients.

Another factor postulated to contribute to the formation of illness representations is survivors' perceived risk of their cancer recurring [30-31]. Perceived risk of breast cancer recurrence is a personal risk judgment (usually captured as a numerical number or percent) made about the probability that breast cancer will return [30]. Such judgments are a key part of illness representations. Whether the patient judges her risk to be high or low, relative to actual risk of recurrence, appears related to the degree that she pursues behaviors to minimize potential outcomes from an illness threat [7]. To date, in spite of possible interactions, little is known about the relationship between risk perception and fear of breast cancer recurrence among breast cancer survivors. Thus, the purpose of this study was to examine the relationships between breast cancer survivors' illness representations, perceived risk of recurrence, demographic and clinical characteristics, and their FOQR.

### *Theoretical Framework and Design*

Illness representations, risk perception and fear of cancer recurrence

The *Common Sense Model of Illness Representations* developed by Leventhal and colleagues [23-24] guided our development of a conceptual model for this study (see *Figure 1*). According to the model, breast cancer survivors with certain characteristics (e.g. higher anxiety), illness representations (e.g. greater emotional representation) and higher perceived risk are likely to experience higher levels of FOCR.

## **METHODS**

### *Design and Sample*

This study used a cross-sectional descriptive correlational design to examine the relationships among study variables. We used a web-based survey to collect data from survivors recruited from internet-based discussion boards in an attempt to locate longer-term breast cancer survivors who may not be attending local cancer clinics. Our survey was administered using Qualtrics Survey Software®, an online survey platform used widely for Internet distribution/collection of data. We recruited women from the following three Internet breast cancer discussion boards: 1) Komen for the Cure™, 2) Young Survival Coalition™ and 3) Network of Strength™. Prior to recruiting subjects the IRB at the University of Michigan approved the study and we obtained permission from each site to recruit subjects off their discussion boards.

## Illness representations, risk perception and fear of cancer recurrence

Women were eligible to take part in the study if they were diagnosed and treated for any stage of breast cancer (Stage 0-IV) at least one year ago. Women were excluded if they were currently in treatment for their primary diagnosis of breast cancer, or entered the study but did not complete the fear of recurrence questionnaire. Patients with advanced disease (i.e. stage IV) were also eligible for the study if they reported that they were not in active treatment for new disease progression. A priori power analysis using G\*power 3.1 [32] indicated that a sample of at least 119 participants would be required to detect a relatively small effect size ( $ES=.3$ ; [33]), using 80% power and an  $\alpha$  of 0.05.

### *Measures*

We used the State Trait Anxiety Inventory-Trait (STAI-T)© form Y-2 for adults to measure trait anxiety. This scale has been used widely to measure the trait of anxiety in many different patient populations [34]. It consists of 20 self-rating statements on a Likert type scale with 1=almost never to 4 =almost always. Nine items of the twenty are reversed scored. This scale has longstanding documented test–retest reliability, validity, and internal consistency  $\alpha=0.90$  [43]. In the current study the Cronbach alpha coefficient was .92.

We used two instruments to measure Illness representations and risk perceptions. The first was the Illness Perception Questionnaire-Revised (IPQ-R),

Illness representations, risk perception and fear of cancer recurrence

a widely used quantitative measure of illness representations [35]. The IPQ-R, uses one dichotomous scale and six 5 point Likert type scales ranging from strongly disagree to strongly agree wherein scores can range from 0-30. Seven domains assess: 1) Timeline - cyclical, acute/chronic how long will the illness last and if so will it continue as a sustained issue or be cyclical in nature. 2) Control, how much personal and treatment control do they have or not have over the outcomes of their illness. 3) Consequences how much did and will this affect their current and future life (Personal, Treatment). 4) Emotional representation is an assessment of emotional responses, or a measure of the emotional impact generated by the illness. 5) Illness identity or how many symptoms are thought to be associated with a diagnosis (symptom attribution). 6) Illness cohesion how much understanding and a clear picture of the illness. 7) Cause, things they believe caused or contributed to the occurrence of their illness. All of these components, in different combinations, have been used previously to identify persons experiencing more distress or less control over their illness [7, 23-29]. In prior research, internal consistency reliabilities of the IPQ-R subscales (scored as continuous variables), ranged from  $\alpha = 0.79-0.89$  and had adequate validity [35]. The internal consistency reliability of the subscales used in this study were  $\alpha = 0.72 - 0.87$ .



Illness representations, risk perception and fear of cancer recurrence

To measure risk perception we adapted three Likert-scale items previously used and validated [36, 37]. The items ask participants 1) how much they feel they are in control over the possibility of their breast cancer recurring, 2) how likely they feel that other women will have a breast cancer recurrence, and 3) how likely they feel that they themselves will have a recurrence. In addition, women were asked to estimate their perception of the chance, in the form of a numerical percentage (0-100%), which their breast cancer would recur. All four items were used as individual stand-alone scales.

The Fear of Recurrence Questionnaire (FRQ) is a 22-item instrument designed to measure survivors' fear of recurrence using a 5-point Likert type scale that ranges from strongly agree to strongly disagree [8]. Scores are summed to give an overall score. Higher scores indicate more fear of recurrence. The questionnaire was specifically designed for use with breast cancer survivors to measure FOCR. An internal consistency of  $\alpha=0.92-0.95$  with breast cancer survivors has been reported [8, 16, 38]. In the current study the Cronbach alpha coefficient was 0.90.

The survey instrument also collected selected demographic and clinical information. The demographic information included: 1) age; 2) race; 3) marital status; 4) education level; 5) employment status and 6) income level. Clinical information consisted of: 1) time since diagnosis; 2) type and stage of breast

Illness representations, risk perception and fear of cancer recurrence

cancer at diagnosis; 3) number and type of surgical interventions; 4) if women received adjuvant chemotherapy; 5) if women received radiation therapy; 6) if women had or were currently on adjuvant estrogen depriving therapy, and 7) the presence and effect of co-morbidities.

#### Data Collection

We invited discussion board members to participate in the study through posting of the study link and participation of the investigator in ongoing discussions. Once a survivor chose to participate in the study she either clicked on the link provided or was emailed the link by the PI. Completion time for the survey took between 35-60 minutes with the average being around 40 minutes. Women who completed the survey were also encouraged, at completion, to invite friends and acquaintances to participate in the study in order to create a snowball recruitment effect.

#### Data Analysis

Statistical analysis was done using IBM SPSS 22 (formerly SPSS 22). We used mean substitution for missing data when the proportion of missing data was very small (<.05%) and of a random nature [39]. However, there was considerable missing data for participants' age (57.3%) and as a result mean substitution for age was not acceptable. Also participants' perception of the

Illness representations, risk perception and fear of cancer recurrence

chance of a cancer recurrence expressed as a numerical percentage, had considerable missing data (30%) with women typing in qualitative comments about their risk rather than a percent. Because of the considerable amount of missing data, age and the numerical percent for perceived risk of cancer recurrence were only used to describe sample characteristics and not included in model testing. Results were not substantially changed when dummy coding and mean substitution was used for other variables.

Race was also excluded from model testing because of the uneven data distribution in racial categories. Non-Hispanic Whites comprised 95.7% of the subjects while the remaining 4.3% of the subjects were distributed among three other categories of the variables (African American 1.7%, Native American 1.7% other .9%). Dichotomizing the variable into two levels (Non-Hispanic White and other) would not have resolved this uneven distribution; therefore, it was only used for descriptive statistics [39].

Model testing was conducted in two steps. First we assessed the correlations among the major study variables and FOQR to identify the nature of relationships and variable entry into a regression equation. Second, we used hierarchical regression to determine the amount of variance each conceptual model factor contributed to predicting FOQR.

## Results

### *Sample Description*

Women (N=178) from three breast cancer Internet discussion boards entered the web-based survey and 121 subjects finished the survey (response rate of 68%). However, during data cleaning four further cases were excluded due to a large amount of missing data. A final sample (N=117) was used for data analysis. Most women were between 46-55 years of age, Caucasian (93%), resided in the USA (82%), were partnered (74%), had a bachelors or higher degree (56%), and were middle to upper class with an average house hold income of > \$80,000 (48%). About one-half were employed full time (47%).

Most women were diagnosed and treated for their breast cancer within two years ( $M=2.71$ , range 1-10 years) and reported having had an invasive cancer (76%), a mastectomy (68%), adjuvant chemotherapy (79%), and radiation therapy (69%). The sample was evenly distributed between those who had one (46%) or more surgeries (54%), and those treated with or currently on adjuvant estrogen therapy (47%). The majority of women were diagnosed as a stage II or higher (60.5%) with ten women (9%) self-disclosing that they had had a breast cancer recurrence.

### *Relationship among study variables*

## Illness representations, risk perception and fear of cancer recurrence

Prior to model testing we examined the individual correlations between the predictor variables (demographic and medical characteristics, illness representations, and risk perception) and FOCR (see Table 1). Only one survivor characteristic (trait anxiety) and two medical characteristics (years since treatment, radiation therapy) had significant correlations with FOCR and were retained for the regression model. Higher levels of trait anxiety were associated with higher levels of FOCR ( $r=.443$ ,  $p<.01$ ). Women who were more years away from treatment had lower levels of FOCR ( $r=-.295$ ,  $p<.01$ ), as did women who received radiation therapy ( $r=-.300$ ,  $p<.01$ ). Types of cancer (carcinoma in situ, invasive etc.) along with all other survivor characteristic (Model 1) were not significantly correlated with FOCR and therefore were dropped from model testing.

Fear of recurrence, illness representations and *perceived self risk* were also correlated with each other (see Table 1). Among the components of illness representation, higher fear of recurrence was reported only among women who: perceived an associated chronic timeline ( $r=.45$ ,  $p<.01$ ), cyclical timeline ( $r=.20$ ,  $p<.05$ ), perceived more overall consequences ( $r=.51$ ,  $p<.01$ ), along with both personal ( $r=-.20$ ,  $p<.05$ ), and treatment consequences ( $r=-.22$ ,  $p<.05$ ), attributed more symptoms to their breast cancer ( $r=.452$ ,  $p<.01$ ), and had more of an emotional representation of their breast cancer ( $r=.627$ ,  $p<.01$ ). With regard to

Illness representations, risk perception and fear of cancer recurrence

risk perception, women who perceived that they were at higher risk of developing a recurrence also had a greater level of fear of recurrence ( $r=.314$ ,  $p<.01$ ). These seven illness representation components and perceived risk were therefore retained for the standard regression analyses.

### *Model Testing*

We tested our model using standard regression analysis followed by hierarchical regression analysis to determine if patient characteristics (years since treatment & radiation therapy), trait anxiety (STAI-T), *illness representations (seven retained components of IPQ-R)*, and *risk perceptions predicted levels of FOCR*. Preliminary analyses were conducted to ensure no violation of assumptions of normality, linearity, multicollinearity, and homoscedasticity. Only those variables that had a moderately or higher significant bivariate correlation ( $r\geq.20$ ) with FOCR (see Table 1) were included in the initial regression model.

The model explained a total of 62% of the variance ( $F(10, 106)=17.27$ ,  $p<.01$ ) in fear of recurrence (see Table 2). However, only four of the eleven variables, radiation therapy ( $\beta=-.14$ ,  $p<.03$ ), timeline ( $\beta=.21$ ,  $p<.01$ ), emotional representations ( $\beta=.44$ ,  $p<.01$ ), and symptom attribution ( $\beta=.21$ ,  $p<.01$ ), had significant independent coefficients while the coefficient for consequences

Illness representations, risk perception and fear of cancer recurrence

( $\beta=.16$ ,  $p<.07$ ), treatment consequences ( $\beta=.15$ ,  $p<.06$ ) and self risk ( $\beta=.13$ ,  $p<.07$ ) approached significance.

Next we conducted a hierarchical regression analysis using our conceptual model (Figure 1) as a guide. All significant variables were entered in blocks one representing survivorship characteristics and the second representing illness representations. Table 3 indicates that the identified survivorship characteristics accounted for 29% of the variance ( $F(3, 113)=15.49$ ,  $p<.01$ ) in fear of recurrence and all had significant independent coefficients. When illness representations were added they accounted for 62% of the variance ( $F(8, 105)=11.64$ ,  $p<.01$ ). However, only one of the three survivorship characteristics, radiation ( $\beta=-.14$ ,  $p<.02$ ), retained its significant independent coefficient the other two. Of the eight variables representing illness representations only timeline ( $\beta=.23$ ,  $p<.01$ ), consequences ( $\beta=.16$ ,  $p<.03$ ), emotional representations ( $\beta=.46$ ,  $p<.01$ ) and symptom attribution ( $\beta=.21$ ,  $p<.01$ ) were found to have significant independent coefficients in the model. These findings indicate that demographic/clinical characteristics may not be as important as the domains of illness representations in predicting FOQR.

### *Discussion*

## Illness representations, risk perception and fear of cancer recurrence

Illness representations appear to account for a significant amount of variance in women's fear of breast cancer recurrence as predicted in our conceptual model. Four of the seven main components of illness representations in our model (i.e. emotional representations, symptom attribution, consequences, and timeline) were found to significantly contribute to FOCR. These findings are similar to others [29, 41], who found that cause, control/cure, consequences and symptom attribution were related to increased levels of distress in cancer survivors.

Previous studies have not measured emotional representations that, not surprisingly, had a significant association with FOCR in this study. Fear that cancer may return will likely evoke emotional responses such as feelings of depression, anger, anxiousness, and worry [35]. Emotional representations refer to how much the current illness generates these increased emotional responses. It is likely that women who experience greater emotional upset with their current cancer are likely to continue to have increased emotional responses when they consider the possibility of cancer recurring in the future. This finding however, may be specific to frequent users of Internet discussion boards alone. Emerging from treatment of breast cancer with a strong emotional representation of the cancer experience (i.e., increased upset) may prompt these women to seek



Illness representations, risk perception and fear of cancer recurrence

support on the Internet. By contrast, women who have less of an emotional representation of their disease may be less likely to participate in this activity.

A higher timeline score, an indicator that women may feel that their breast cancer will last a long time [35], was significantly correlated with an increase in FOCR. This suggests that women who think that cancer will be an ongoing issue in their lives will have more FOCR. These women have already experienced the effects of cancer treatment on their lives and the *fear* that it may still be lurking ready to strike again in the future would certainly be associated with more FOCR.

Symptom attribution, or the labeling of any new or old bodily symptoms to a past illness, regardless if the symptom is associated with that illness, [35] was also a strong predictor of FOCR. This relationship to FOCR suggests that women with heightened bodily awareness are more concerned with recurrence. This is a double-edged finding. On one hand being vigilant and reporting concerning symptoms could contribute to earlier successful treatment of a recurrence. On the other hand, it could compel women to seek symptom evaluation from health care providers more frequently than needed [7].

Being diagnosed with cancer has been reported to have consequences that affect a person and their family personally, emotionally, financially, and physically [6-7]. Women who have experienced breast cancer treatment already

Illness representations, risk perception and fear of cancer recurrence

know it disrupted their lives during their initial diagnosis. It was not surprising in our sample that the more women felt that their initial diagnosis of cancer caused consequences in their lives, the more they would be afraid of their cancer coming back to disrupt their lives again.

Our findings that demographic/clinical characteristics may not be as important as other factors in predicting FOCR in breast cancer survivors are consistent with previous work [29]. In head and neck cancer patients' demographic and clinical factors were unrelated to FOCR yet emotional representations and belief in consequences from having cancer were related [29]. Radiation therapy, however, was the one clinical factor that was related to FOCR suggesting that women who undergo radiation therapy may have less FOCR at the end of treatment. This finding could be a manifestation of the perception that more treatment is better at ensuring no disease recurrence or progression in the future [8-10]. Radiation therapy is typically only given to patients who undergo a lumpectomy, have extensive disease and/or close margins after mastectomy. In our sample, with more women at stage II or greater, we may have had an unusual proportion of women who underwent mastectomy with radiation therapy. Consequently, this result should be viewed with caution.

Surprisingly, trait anxiety was not a significant predictor of FOCR. The mean trait anxiety score of our sample was no different than the means reported

Illness representations, risk perception and fear of cancer recurrence

for other cancer groups suggesting that women's scores in our study were no higher than other cancer survivors [40]. Although trait anxiety was correlated with fear of recurrence (Table 1), it was not a significant predictor when assessed in conjunction with other study variables within the model (Table 2 & 3). This implies that inherent personality traits, prior to diagnosis and treatment for breast cancer, may not impact on reactions during and after treatment [42] as much as other factors such as emotional representations and symptom attribution.

The current study has several limitations. This sample was very selective and of a homogenous nature with the majority of women being Caucasian, well educated and upper middle class. Self-selection, exclusive recruitment from online sites associated with supportive breast cancer networks, and use of snowball recruitment may have produced sampling bias in this study. Sample bias may have occurred because this sample excludes women who do not participate in these activities or do not have access to the Internet. In addition, due to the cross-sectional design causation cannot be determined. An established theoretical framework, which provided support for our interpretation of the data, guided our study but additional longitudinal studies are needed. Finally, the amounts of missing data in specific items are likely associated with the online data collection methods wherein we did not force a reply from participants to continue in the survey. Therefore, the findings from this study

Illness representations, risk perception and fear of cancer recurrence

preclude generalizing them to other breast cancer populations. This sample may have unique characteristics that are not found in the general population of breast cancer survivors and are specific to online populations only.

### Clinical Implications

FOCR is a common concern of breast cancer patients that appears to be associated with the development of negative illness representations. Greater FOCR was significantly related to several factors such as the development of emotional representations at the end of treatment, increased attribution of symptoms present prior to diagnosis, or resulting from the diagnosis, a higher self perception of risk of recurrence, and a fear of negative consequences. Given these results it is essential to offer psychological counseling and support to address fears about disease recurring as well as other factors that may heighten it. More specifically, clinicians need to normalize women's fears about recurrence and clarify which symptoms are related to cancer from symptoms that are unrelated to it at time of diagnosis and at the end of treatment. In addition discussions on actual risk of recurrence using words (e.g., unlikely, low risk) along with numerical percentages may reassure those women who significantly over-estimate their actual risk [29]. Routine assessment of fear/worry about recurrence during treatment could help identify a subset of women with significant ongoing issues requiring referral to supportive services and in effect

Illness representations, risk perception and fear of cancer recurrence

mitigate an overly emotional representation of the breast cancer experience. In survivorship care assurances of further treatment options should cancer recur, may help decrease breast cancer survivors FOCR as well.

Women who do not receive the information and support that they need to manage their fears within the healthcare system may seek other means of support by frequenting Internet support sites. As valuable as the Internet may be it can also be a source of misinformation and may even contribute to a higher level of fear. Specifically many triggers are found online that could bombard frequent users, increasing rather than alleviating their distress [12].

## **Conclusion**

Future research should seek to develop new methods to identify and then to intervene with cancer patients, while in treatment and during early survivorship, to mitigate the development of distress in survivorship from an amplified level of FOCR. Further research should also investigate if the factors that accounted for a significant amount of variance in fear of recurrence in this study are relevant for survivors with other types of cancer as well as breast cancer survivors who do not participate in online discussion boards/forums. Lastly, a closer examination of potential relationships between FOCR, social support, Internet usage, and

Illness representations, risk perception and fear of cancer recurrence

utilization of resources may shed some light on how clinical practice during treatment can be altered to support women as they transition into survivorship.

Author Manuscript

## References

- [1] American Cancer Society. *Breast cancer facts & figures 2013-2014*. American Cancer Society: Atlanta, 2013.
- [2] Alder NE, Page AEK. *Cancer care for the whole patient: Meeting psychosocial healthcare needs*. National Academies Press: Washington, D.C., 2008.
- [3] Crist, JV. Grunfeld, BA. Factors reported to influence fear of recurrence in cancer patients: a systematic review. *Psycho-Oncology* 2013; **22**:978–986. doi: 10.1002/pon.3114
- [4] Koch L. Bertram H.,..... & Arndt V. Fear of recurrence in long-term breast cancer survivors-still an issue. Results on prevalence, determinants, and the association with quality of life and depression from the Cancer Survivorship -a multi-regional population-based study. *Psycho-Oncology* 2014; **23**:547–554. doi: 10.1002/pon.3452
- [5] Koch L. Jensen L. Brenner H. Arndt V. Fear of recurrence and disease progression in long-term ( $\geq 5$  years) cancer survivors-a systematic review of quantitative studies. *Psycho-Oncology* 2013; **22**:1-11. doi:10.1002/pon.3022
- [6] Wolff, SN. Nichols, C. Ulman, D. Miller, A. Kho, S. Lofye, M. . . . Armstrong, L. Survivorship: an unmet need of the patient with cancer- implication of a survey of the Lance Armstrong Foundation (LAF). *Journal of Clinical Oncology, 2005 ASCO Annual Meeting Proceedings* 2005; **23**: 6032.
- [7] Lee-Jones, C. Humphris, G. Dixon, R. Hatcher, M. Fear of cancer recurrence: A literature review and proposed cognitive formulation to explain exacerbation of recurrence fears. *Psycho-Oncology* 1997; **6**:95-105.
- [8] Northouse, LL. Mastectomy patients and the fear of cancer recurrence. *Cancer Nursing* 1981; **4**:213-220.
- [9] Van den Beuken-van Everdingen, M. Peters, M. Rijke, J. Schouten, H. van Kleef, M. Patijin, J. Concerns of former breast cancer patients about disease recurrence: A validation and prevalence study. *Psycho-Oncology* 2008; **17**: 1137-1145. doi: 10.1002/pon.1340
- [10] Vickberg S. Fears about breast cancer recurrence, interviews with a diverse sample *Cancer Practice* 2001; **9**: 237-243.

- [11] Janz NK. Hawley ST. Mujahid MS. Griggs JJ. Alderman A. Hamilton AS> Graff JJ. Jaggi R. Phil D. Katz SJ. Correlates of worry about recurrence in a multi-ethnic population –based sample of women with breast cancer. *Cancer* 2011; **117**:1827-1839. doi:10.1002/cncr.25740.
- [12] Simard, S. Savard, J. Ivers, H. Fear of cancer recurrence: Specific profiles and nature of intrusive thoughts. *Journal of Cancer Survivorship* 2010; **4**: 361-371. doi: 10.1007/s11764-010-0136-8
- [13] Abeloff, M. Derogatis, LR. Psychological aspects of the management of primary and metastatic breast cancer. *Progress in Clinical and Biological Research* 1977; **12**:505-516.
- [14] Greer, S. Psychological consequences of cancer. *The Practitioner* 1979; **222**:173-178.
- [15] Weisman, AD. Early diagnosis of vulnerability in cancer patients. *The American Journal of the Medical Sciences* 1976; **271**:187-196
- [16] Black, EK. White, CA. Fear of recurrence, sense of coherence and posttraumatic stress disorder in haematological cancer survivors. *Psycho-Oncology* 2005;**1**:510-515.
- [17] Costanzo, ES. Lutgendorf, SK. Mattes, ML. Trehan, S. Robinson, CB. Tewfik, F. Roman, SL. Adjusting to life after treatment: Distress and quality of life following treatment for breast cancer. *British Journal of Cancer* 2007; **97**: 1625-1631. doi: 10.1038/sj.bjc.6604091.
- [18] Simard, S. Savard, J. Fear of cancer recurrence inventory: development and initial validation of a multidimensional measure of fear of cancer recurrence. *Support Care Cancer* 2009; **17**:241-251
- [19] Thewes B. Bell ML. Butow P. Beith J. Boyle F. Friedlander M. McLachlan SA. Psychological morbidity and stress but not social factors influence level of fear of cancer recurrence in young women with early breast cancer: results of a cross-sectional study. *Psycho-Oncology* 2013; **22**:2797-2806. doi:10.1002/pon.3348
- [20] Thewes B. Brebach R. Dzikowska M. Rhodes P. Sharpe L. Butow P. Current approaches to managing fear of cancer recurrence; a descriptive survey of psychosocial and clinical health professionals. *Psycho-Oncology* 2014; **23**:390-396. doi: 10.1002/pon.3423



- [21] Custers, J.A.E., Becker, E.S., Gielissen, M.F.M., Van Laahoven, H.W.M., Rinck, M., Prins, J.B. Selective Attention and Fear of Cancer Recurrence in Breast Cancer Survivors. *Annals of Behavioral Medicine* 2014; **05** online: doi: 10.1007/s12160-014-9632-9
- [22] Vachon, M. Psychological distress and coping after cancer treatment: How clinicians can assess distress and which interventions are appropriate—what we know and what we don't. *American Journal of Nursing* 2006; **106**:26-31.
- [23] Leventhal, H. Meyer, D. Nerenz, D. The common sense representation of illness danger. In *Contributions to Medical Psychology*, Rachman, S. (ed), vol.2. Pergamon Press:New York, 1980; 7-30.
- [24] Leventhal, H. Brissette, I. Leventhal, E. The common-sense model of self-regulation of health and illness. In *The Self-Regulation of Health and Illness Behavior*, Cameron LD & Leventhal H (eds.). Routledge: New York, 2003;42-64.
- [25] Hagger, M.S. Orbell, S. A meta-analytic review of the common-sense model of illness representations. *Psychological Health* 2003; **18**:141-184.
- [26] Rozema H. Völlink T. Lechner L. The role of illness representations in coping and health of patients treated for breast cancer. *Psycho-Oncology* 2009; **18**: 849-857. doi: 10.1002/pon.1488
- [27] Costanzo ES. Lutgendorf SK. Roeder SL. Common-sense beliefs about cancer and health practices among women completing treatment for breast cancer. *Psycho-Oncology* 2010; **20**:53-61. doi: 10.1002/pon.1707
- [28] Anagnostopoulous F. Spanea E. Assessing illness representations of breast cancer a comparison of patients with healthy and benign controls. *Journal of Psychosomatic Research* 2005; **58**:327-334. doi: 10.1016/j.jpsychores.2004.09.011
- [29] Llewellyn, C. Weinman, J. McGurk, M. Humphris, G. Can we predict which head and neck cancer survivors develop fears of recurrence? . *Journal of Psychosomatic Research* 2008; **65**:525-532. doi: 10.1016/j.jpsychores.2008.03.014
- [30] Liu Y. Pérez, MLAR. Massman K. Robinson E. Myles S. . . . Jeffe DB. Accuracy of perceived risk of recurrence among patients with early stage breast cancer. *Cancer Epidemiology Biomarkers & Prevention* 2010; **19**:675-680. doi: 10.1158/1055-9965.EPI-09-1051

Illness representations, risk perception and fear of cancer recurrence

- [31]Rakovitch E. Franssen EJK. Ackerman I. Pignol J-P. Paszat L. . . . Redelmeier DA. A comparison of risk perception and psychological morbidity in women with ductal carcinoma in situ and early invasive breast cancer. *Breast Cancer Research and Treatment* 2003; **77**:285-293.
- [32]Faul F. Erdfelder E. Buchner A. Lang AG. *Statistical power analysis using G\*Power 3.1: Tests for correlation and regression analyses. Behavior Research Methods* 2009; **41**:1149-1160. doi: 10.3758/BRM.41.4.1149
- [33]Cohen J. (1992). Statistical power analysis. *Current Directions in Psychological Science* 1992; **1**:98-101.
- [34]Spielberger, C. D. State trait anxiety inventory for adults. *Sampler set, manual, instrument and scoring guide* 1983. Retrieved from Transform by Mindgarden website: <https://www.mindgarden.com/participant>
- [35]Moss-Morris, R. Weinman, J. Petrie, KJ. Horne, R. Cameron, L. Buick, D. The revised illness perception questionnaire (IPQ-R). *Psychology and Health* 2002; **17**:1-16. doi: 10.1080/08870440290001494
- [36]Katapodi MC. Dodd MJ. Lee KA. Facione NC. Underestimation of breast cancer risk: Influence on screening behavior. *Oncology Nursing Forum* 2009; **36**:306-314 doi: 10.1188/09.ONF.306-314
- [37]Katapodi MC. Dodd M. Facione N. Lee K. Humphreys J. Why some women have an optimistic or a pessimistic bias about their breast cancer risk? Experiences, heuristics, and knowledge of risk factors. *Cancer Nursing* 2010; **33**:64-73. doi: 10.1097/NCC.0b013e3181b430f9.
- [38] Hilton A. The relationship of uncertainty, control, commitment, and threat of recurrence to coping strategies used by women diagnosed with breast cancer. *Journal of Behavioral Medicine* 1988; **12**:39-54.
- [39]Tabachnick BG. Fidell LS. *Using Multivariate Statistics 5th Edition*. Pearson: Toronto, Ontario: 2007.
- [40]Harrison, SE. Watson, EK. Ward, AM. Khan, NF. Turner, D. Adams, E. . . .Rose, PW. Primary health and supportive care needs of long-term cancer survivors: A questionnaire survey. *Journal of Clinical Oncology* 2011; **29**:2091-2098. doi: 10.1200/JCO.2010.32.5167
- [41]Millar, K., Purushotham, AD. McLatchie, E. George, WD. Murraray, G. D. A 1-year prospective study of individual variation in distress and illness

Illness representations, risk perception and fear of cancer recurrence

perceptions after treatment for breast cancer. *Journal of Psychosomatic Research* 2005; **58**:335-342. doi: 10.1016/j.jpsychores.2004.10.005

[42]Lebel, S. Beattie, S. Arès I. Bielajew C. Young and worried:age and fear of recurrence in breast cancer survivors.*Health Psychology* 2013; **32**:695-705. doi: 10.1037/a00

**Acknowledgements:**

This work was supported in part with funding from Sigma Theta Tau –Upsilon Chapter, Rackham Graduate School-University of Michigan and The American Academy of Nurse Practitioners. Our gratitude also goes out to Dr. Dale Rajacich for her excellent editing of this article.

**Conflict of interest:**

There are no conflicts of interests from any author.

Author Manuscript

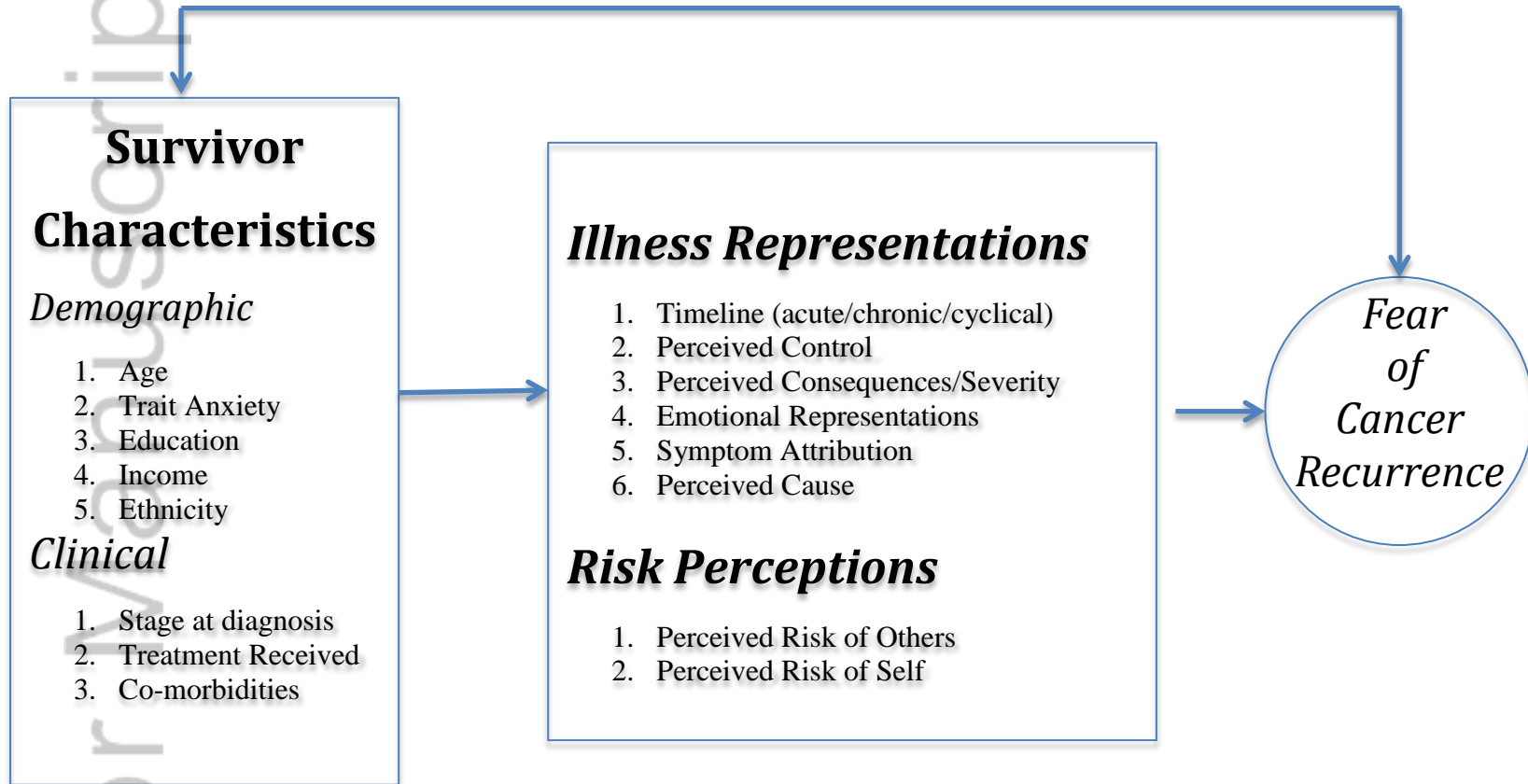


Figure 1: Breast Cancer Survivorship Model of Predictors of Fear of Recurrence

Illness representations, risk perception and fear of cancer recurrence

Table 1

*Correlation Matrix for Fear of Cancer Recurrence (FRQ) and Significant Characteristics, Trait Anxiety (STAI-T), Illness Perceptions (IPQ-R), and Risk Perceptions (RP1-3)*

Measure	Fear of Cancer Recurrence	Years since treatment	Radiation therapy	Trait Anxiety	Timeline	Time Cyclical	Consequences	Personal Consequences	Treatment Consequences	Emotional Representation	Symptom Attribution	Self Risk
Fear of Cancer Recurrence	1											
Years since treatment	-.29**	1										
Radiation therapy	-.30**	.00	1									
Trait Anxiety	.44**	-.13	-.16	1								
Timeline	.45**	-.22*	-.03	.27**	1							
Time Cyclical	.20*	-.08	-.15	.04	.32**	1						
Consequences	.51**	-.32**	-.09	.27**	.34**	.17	1					
Personal Consequences	-.20*	.03	.01	-.35**	-.33**	-.12	-.10	1				
Treatment Consequences	-.22*	.05	.02	-.22*	-.54**	-.23**	-.22*	.47**	1			
Emotional Representations	.62**	-.16	-.18	.57**	.22*	.25**	.43**	-.25**	-.19*	1		
Symptom Attribution	.35**	-.26*	-.29**	.27**	.29**	.19*	.24**	-.16	-.25**	.20*	1	
Self Risk	.31**	-.18	-.05	.11	.53**	.13	.25**	-.27**	-.40**	.04	.28**	1

\*\* . Correlation is significant at the 0.01 level (2-tailed). \* . Correlation is significant at the 0.05 level (2-tailed).

Illness representations, risk perception and fear of cancer recurrence

Table 2

Summary of Standard Multiple Regression of all significant predictors for Fear of Recurrence (FRQ)(N=117)

Variable	B	SE	$\beta$	t	P
Years since Treatment	-.22	.37	-.04	-.59	.56
Radiation	-2.09	.97	-.14	-2.17	<b>.03</b>
Trait Anxiety	.05	.10	.04	.52	.60
Time Line	.51	.20	.21	2.55	<b>.03</b>
Time Cyclical	-.32	.27	-.07	-1.15	.25
Consequences	.53	.24	.16	2.17	<b>.07</b>
Personal Consequences	-.01	.21	-.01	-.06	.95
Treatment Consequences	.65	.33	.15	1.87	<b>.06</b>
Emotional Representations	1.23	.22	.44	5.53	<b>.01</b>
Symptom Attribution	.71	.24	.21	2.93	<b>.01</b>
Self Risk	.82	.47	.13	1.73	<b>.07</b>

Linear regression of all variables with significant correlations at the 0.05 level,  $R^2 = .620$  (62%); constant =16.7

Author Manuscript

Illness representations, risk perception and fear of cancer recurrence

Table 3

Summary of Hierarchical Regression Analysis for variables predicting Fear of Recurrence (FRQ)(N=117)

Variable	Model 1			Model 2		
	B	SE B	$\beta$	B	SE B	$\beta$
Years since Treatment	-1.23	.46	<b>-.21**</b>	-.22	.37	-.04
Radiation Therapy	-3.56	1.2	<b>-.23**</b>	-2.2	.97	<b>-.14*</b>
Trait Anxiety	.51	.11	<b>.38**</b>	.03	.11	.02
Timeline				.56	.21	<b>.23**</b>
Time Cyclical				-.32	.28	-.08
Consequences				.52	.24	<b>.16*</b>
Personal Consequences				-.02	.21	-.01
Treatment Consequences				.63	.35	.14
Emotional Representations				1.30	.23	<b>.46**</b>
Symptom Attribution				.73	.24	<b>.21**</b>
Self Risk				.79	.47	.12
R <sup>2</sup>		.29			.62	
F for change in R <sup>2</sup>		<b>15.49**</b>			<b>11.64**</b>	

\*p < .05. \*\*p < .01.

Auto-Medical