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

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#### **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, and 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.

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# **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 1970s, 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 [12–14]. 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 [4,7,8,15–18]. 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 [8–10,18–21].

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 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 [3,4,18–21].

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 [22–24]. 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 [22–24]. These appraisals determine the development of illness representations and shape future responses to illness threats along with dictating health behaviors [22–24].

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Although research on illness representations within oncology has produced mixed results, because of different instruments used and endpoints assessed [25–28], some evidence indicates that illness representations may affect FOCR among cancer survivors [28]. Breast cancer patients with more of an emotional representation of their disease had a poorer perception of their overall physical and mental health [25]. Furthermore head and neck cancer patients with an illness representation of more severe consequences associated with their cancer and who also held stronger emotional representations of their illness had greater FOCR [28]. No relationship was found between demographic or objective medical factors and patients' ongoing FOCR. 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 [29,30]. 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 [29]. 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 FOCR.

# Theoretical framework and design

The Common Sense Model of Illness Representations developed by Leventhal and colleagues [22,23] 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: (a) Komen for the Cure <sup>™</sup>, (b) Young Survival Coalition <sup>™</sup>, and (c) Network of Strength <sup>™</sup>. 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.

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

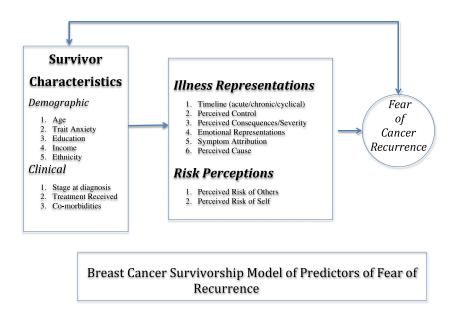


Figure 1. Breast cancer survivorship model of predictors of fear of recurrence

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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 [31] indicated that a sample of at least 119 participants would be required to detect a relatively small effect size (ES=.3; [32]), using 80% power and an  $\alpha$  of 0.05.

#### Measures

We used the State Trait Anxiety Inventory-Trait (STAI-T)  $\odot$  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 [33]. It consists of 20 self-rating statements on a Likert type scale with 1=almost never to 4=almost always. Nine items of the 20 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), a widely used quantitative measure of illness representations [34]. 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 to 30. Seven domains assess: (a) 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. (b) Control, how much personal and treatment control do they have or not have over the outcomes of their illness. (c) Consequences, how much did and will this affect their current and future life (Personal, Treatment). (d) Emotional representation is an assessment of emotional responses, or a measure of the emotional impact generated by the illness. (e) Illness identity or how many symptoms are thought to be associated with a diagnosis (symptom attribution). (f) Illness cohesion, how much understanding and how clear a picture of the illness. (g) 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 [7,22–28]. In prior research, internal consistency reliabilities of the IRQ-R subscales (scored as continuous variables), ranged from  $\alpha = 0.79 - 0.89$  and had adequate validity [34]. The internal consistency reliability of the subscales used in this study were  $\alpha = 0.72 - 0.87$ .

To measure risk perception we adapted three Likert-scale items previously used and validated [35,36]. The items ask participants (a) how much they feel they are in control over the possibility of their breast cancer recurring, (b) how likely they feel that other women will have a

breast cancer recurrence, and (c) 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 [8,15,37]. 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: (a) age, (b) race, (c) marital status, (d) education level, (e) employment status, and (f) income level. Clinical information consisted of: (a) time since diagnosis, (b) type and stage of breast cancer at diagnosis, (c) number and type of surgical interventions, (d) if women received adjuvant chemotherapy, (e) if women received radiation therapy, (f) if women had or were currently on adjuvant estrogen depriving therapy, and (g) 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 and 60 min with the average being around 40 min. 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 [38]. 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 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

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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 were 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 [38].

Model testing was conducted in two steps. First we assessed the correlations among the major study variables and FOCR 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 FOCR.

## 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 because of a large amount of missing data. A final sample (N=117) was used for data analysis. Most women were between 46 and 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

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 anxiety) (trait and two

	Fear of	Years										
	Cancer	since	Radiation	Trait		Time		Personal	Treatment	Emotional	Symptom	Self
Measure	Recurrence	treatment	therapy	Anxiety	Timeline	Cyclical	Cyclical Consequences	Conseduences	Consequences	Representation	Attribution	Risk
Fear of cancer recurrence	_											
Years since treatment	29	_										
Radiation therapy	30**	00:	_									
Trait anxiety	**+++:	13	16	_								
Timeline	.45**	22*	03	.27**	-							
Time cyclical	.20*	08	15	40.	.32**	_						
Consequences	** 5:	32**	09	.27**	.34**	71.	_					
Personal consequences	20*	.03	10:	35**	33**	12	01	_				
Treatment consequences	22*	.05	.02	22*	54**	23**	22*	**/47	_			
Emotional representations	.62**	16	81	:57**	.22*	.25**	.43**	25**	*61	_		
Symptom attribution	.35**	26*	29	.27**	.29**	*6 .	.24**	16	25**	.20*	_	
Selfrisk	** E:	81	05	Ξ.	.53**	.I.3	.25**	27**	40**	40.	.28**	-

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

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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 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 and 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 ( $r \ge .20$ ) 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 ( $\beta = .16$ , 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

**Table 2.** Summary of Standard Multiple Regression of all significant predictors for Fear of Recurrence (FRQ) (*N* = 117)

Variable	В	SE	β	t	Р
Years since treatment	22	.37	04	59	.56
Radiation	-2.09	.97	14	-2.17	.03
Trait anxiety	.05	.10	.04	.52	.60
Time line	.51	.20	.21	2.55	.03
Time cyclical	32	.27	07	-1.15	.25
Consequences	.53	.24	.16	2.17	.07
Personal consequences	0 I	.21	OI	06	.95
Treatment consequences	.65	.33	.15	1.87	.06
Emotional representations	1.23	.22	.44	5.53	.01
Symptom attribution	.71	.24	.21	2.93	.01
Self risk	.82	.47	.13	1.73	.07

Linear regression of all variables with significant correlations at the 0.05 level, R<sup>2</sup> = .620 (62%): constant = 16.7

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. 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 FOCR.

**Table 3.** Summary of Hierarchical Regression Analysis for variables predicting Fear of Recurrence (FRQ) (N = 117)

		Model I			Model 2	2
Variable	В	SE B	β	В	SE B	β
Years since treatment	-I.23	.46	21**	22	.37	04
Radiation therapy	-3.56	1.2	23**	-2.2	.97	14*
Trait anxiety	.51	.11	.38**	.03	.11	.02
Timeline				.56	.21	.23**
Time cyclical				32	.28	08
Consequences				.52	.24	.16*
Personal consequences				02	.21	0 I
Treatment consequences				.63	.35	.14
Emotional representations				1.30	.23	.46**
Symptom attribution				.73	.24	.21**
Self risk				.79	.47	.12
$R^2$		.29			.62	
f for change in r <sup>2</sup>		15.49**			11.64**	

<sup>\*</sup>p < .05.

<sup>\*\*</sup>p < .01.

#### **Discussion**

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 [28,39], 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 [34]. 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 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 [34], 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, [34] 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 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 [28]. 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 [28]. 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 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 (Tables 2 and 3). This implies that inherent personality traits, prior to diagnosis and treatment for breast cancer, may not impact on reactions during and after treatment [41] 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, because of 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 preclude generalizing them to other breast cancer populations. This sample may have unique characteristics that are not found in the

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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 overestimate their actual risk [28]. 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 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 [42].

## 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. Last, a closer examination of potential relationships between FOCR, social support, Internet usage, and utilization of resources may shed some light on how clinical practice during treatment can be altered to support women as they transition into survivorship.

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