

## Long-Term Fear of Recurrence in Young Breast Cancer Survivors and Partners

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## Abstract

**Background:** Fear of a breast cancer recurrence is the most prevalent and disruptive source of distress for long-term survivors and their partners. However, few studies have focused on predictors of fear of recurrence. The aim of this study is to test the efficacy of the Social Cognitive Processing Theory (SCPT) in predicting fear of recurrence in long-term breast cancer survivors diagnosed at age 45 or younger and their partners.

**Methods:** In a large cross-sectional study, breast cancer survivors (N=222) 3-8 years from diagnosis and their partners completed a survey assessing demographic characteristics, fear of recurrence, social constraints, and cognitive processing (intrusive thoughts and cognitive avoidance). Mediation analyses were conducted for survivors and partners separately to determine if cognitive processing would mediate the relationship between social constraints and fear of recurrence.

**Results:** Cognitive processing mediated the relationship between social constraints and fear of recurrence both for survivors [ $F(3,213)= 47.541, R^2=.401, p<.001$ ] and partners [ $F(3,215)= 27.917, R^2=.280, p<.001$ ]. Demographic variables were not significant predictors of fear of recurrence.

**Conclusions:** As predicted, cognitive processing mediated the relationship between social constraints and fear of recurrence. Results expand the utility of the SCPT in long-term survivors and their partners by supporting its use in intervention design.

Keywords: breast cancer, oncology, survivor, partner, fear of recurrence, social constraints

## Background

Breast cancer is the second most common cancer in the world and most frequently diagnosed among women [1]. While breast cancer survivors (BCS) are living longer, disease-free lives, they often have high rates of psychological distress [2]. Of the reported psychological issues resulting from cancer, fear of a breast cancer recurrence (FOR) is one of the most common and most distressing [3]. FOR is additionally related to diminished health-related quality of life and well-being [4], psychiatric morbidity [5], and disruptive symptoms, including sleep disturbance, fatigue, and poor concentration [6]. As many as 55-90% of BCS report FOR throughout survivorship, even many years after treatment [3].

Research has found that those at greatest risk of FOR are BCS diagnosed at a young age [7]. A review of 43 studies found that younger age was the only personal characteristic to consistently predict FOR in BCS [8]. Women diagnosed with breast cancer before age 50 suffer disproportionately from FOR compared to their older counterparts [9] and although rarely studied, young BCS account for approximately 25% of breast cancer diagnoses [10, 11].

In addition to the problems faced by younger BCS, many have partners who also experience cancer-related distress. In fact, partners often report similar or greater psychological distress than BCS [12]. Similar to BCS, their partners often experience high levels of FOR even years after the cancer experience [13]. Mellon et al. (2007) found that FOR in partners accounted for the largest variance in their own quality of life [14]. Partners' FOR has been correlated with their own emotional distress [15] and family stress [14]. Despite the striking evidence of their distress in these studies, partners' long-term outcomes are not often studied.

One theory that has been used successfully to predict distress in cancer survivors, specifically BCS [16], is the Social Cognitive Processing Theory (SCPT) [17-19]. The SCPT asserts that talking about a stressful event, such as cancer, in a supportive social environment facilitates cognitive processing [17]. That is—being able to process the traumatic event cognitively is hypothesized to facilitate psychological adjustment to the stressor. Conversely, the theory proposes that social constraints (family or friends blocking open discussions of the trauma by minimizing concerns, avoiding the person, being critical, or expressing discomfort) [20, 21] can have a negative impact on cognitive processing. If cognitive processing is hindered, the survivor or partner may experience greater negative affect [22], lower self-esteem [23], greater distress, and lower overall QOL in long-term survivorship [16]. Either the survivor or her partner can experience social constraints [21, 22] and the associated negative impact on cognitive processing.

Although the SCPT has been used successfully to predict psychological outcomes in cancer populations, the majority of studies utilizing the theory have only examined outcomes within the first three years post diagnosis [16, 24, 25]. Because psychological distress resulting from cancer—including FOR—can last years after diagnosis, the SCPT may be effective in predicting long-term psychological consequences of cancer.

Additionally, the potential of the SCPT in predicting psychological outcomes in partners has yet to be explored. To our knowledge, only one investigation has examined the impact of social constraints on partners using SCPT [22]. Testing this theory further may provide additional insights into the psychological outcomes of both BCS and partners after the cancer experience. Furthermore, FOR has been linked to several of the constructs within SCPT, including: intrusive thoughts about the cancer [13], cognitive avoidance [26], poor mental health [7], denial [27], and social constraints [24], but has not been tested holistically within the SCPT framework for either BCS or their partners.

The purpose of this study, therefore, is to test theory-based relationships between demographic variables, social constraints, cognitive processing (intrusive thoughts, cognitive avoidance), and FOR through mediation analyses separately in young, long-term BCS and their partners.

## **Methods**

### **Theoretical Framework**

Data for this project were collected for a larger Quality of Life (QoL) study, examining the long-term impact of breast cancer on BCS and their partners. The theoretical framework for that study was adapted from the City of Hope Quality of Life Model Applied to Cancer Survivors, which posited four QoL domains (physical, psychological, social, and spiritual) contributing to overall wellbeing. The model for the parent study proposed a relationship between social constraints and FOR but did not propose a mechanism through which they were related. The SCPT provided a rationale for why those two concepts were related- through cognitive processing.

### **Sample**

Using the Eastern Cooperative Oncology Group (ECOG) database that included 97 sites, we identified eligible BCS. Eligibility criteria included female BCS who: 1) had been diagnosed with breast cancer stages I-IIIa at age 45 years or younger; 2) were 3-8 years past initial treatment at the time of enrollment; 3) did not have a breast cancer recurrence; and 4) had been treated with adjuvant chemotherapy regimen that included Adriamycin, Paclitaxel, and Cyclophosphamide to reduce treatment-related variance. Age eligibility was selected to obtain a sample that was most likely premenopausal at diagnosis [28]. Partners were eligible if they currently lived with the survivor. Eligibility was not limited by partner's gender, nor was information regarding the partner's gender collected.

### **Measures**

Socio-demographic information was collected for both BCS and their partners, including current age, household income, number of co-morbid conditions for BCS, number of chronic conditions for partners, education, race, religious affiliation, and time since diagnosis for BCS. All scales were administered to both BCS and partners.

**Social Constraints** were measured using the Lepore Social Constraints Scale, which asks participants 14 questions on a 1-4 scale, of “never” to “often” regarding the participant’s perception of constraining behaviors from his/her partner in the last four weeks [20]. Total scores range from 14 to 56, with higher scores reflecting greater overall social constraints. Questions include, how often does your partner “avoid you,” “minimize your problems,” and “act uncomfortable when you talk about cancer.” Construct validity has been established previously [20]. Cronbach alpha coefficient for this sample was  $\alpha = .90$ .

**Cognitive Processing** was measured by the Impact of Events Scale [29, 30], which has separate subscales for intrusive thoughts and cognitive avoidance—the components of cognitive processing. Content, construct, and convergent validity have been previously established for the total scale and subscales [29, 30], and has been used as a marker for cognitive processing [17]. The **Intrusive Thoughts** subscale consists of 7 questions, asking participants to indicate how distressing each item has been for him/her during the past four weeks. Responses range zero (not at all distressing) to four (extremely distressing). A total score of all items is taken with higher scores indicating more intrusions. The **Cognitive Avoidance** subscale consists of 8 questions and is scored the same as the intrusion subscale. The combined total score of both subscales produces a total for cognitive processing. Cronbach alpha coefficients for this study were  $\alpha = .887$  for BCS and  $\alpha = .883$  for partners.

**Fear of Recurrence** was measured using the Concerns About Recurrence Scale (CARS) [4]. The first four items of this scale can be summed to produce an overall FOR score. While the CARS includes an additional 28 items, divided into 5 subscales (womanhood, health, death, parenting, and role worries), the partners in our sample were not given all subscales. In order to consistently match partners and BCS, the overall score of the first four items was used for both partners and BCS. Additional analyses were conducted to determine if the subscales rendered unique results from the overall score for BCS, and they did not. The Cronbach alpha for the total scale was  $\alpha = .94$  for the sample.

## **Recruitment Procedures**

The study was approved by the institutional review board of a large Midwestern university, which served as the coordinating site, and from 97 cooperating sites within the Eastern Cooperative Oncology Group (ECOG). Initially, the statistical office for ECOG identified women who met eligibility criteria and forwarded the names to the women’s treating physicians at an ECOG site. The treating physician or designee contacted the women and asked for permission to forward their name and contact information to the coordinating site. If an eligible woman agreed, the university received the contact information and mailed the woman a brochure explaining the study. A research assistant called the survivor and, if verbal consent was obtained, the woman was mailed the informed consent and questionnaire. After agreeing to the study, the survivor was asked if she had a partner who could be contacted about participation. If a partner was available, a brochure was again mailed and phone contact made. Consent and data collection were identical to that of the survivor.

Both the questionnaire and consent were returned in a postage-paid envelope. Follow-up reminder phone calls were made if the survey and informed consent were not received within

two weeks. Of the BCS who agreed to participate, 84% returned data (N=505). Two hundred twenty two partners, representing 54.77% of eligible partners, returned data. Only BCS whose partners participated were included in the present analyses to directly compare survivor and partner scores.

## **Data Analytic Plan**

BCS and partner data were collected and analyzed separately. Descriptive statistics were calculated to determine the presence and severity of FOR in a sample of BCS who were 45 years or younger at diagnosis and their partners, and to describe the demographic, social constraints, and cognitive processing characteristics (cognitive avoidance and intrusive thoughts). Bivariate correlations between all demographic variables (current age, household income, education, race, religious affiliation, and time since diagnosis for BCS) and FOR were run to test for significant relationships. Demographic variables significantly related to FOR ( $p < .25$ ) in bivariate analyses were entered in mediation analyses as recommended by Hosmer and Lemeshaw [31].

Mediation analyses as described by Preacher and Hayes (2004) were conducted to determine if cognitive processing mediated the relationship between social constraints and FOR [32]. The method includes bootstrapping—an empirical method for estimating and testing indirect effect. This method generates a confidence interval (CI) and provides high statistical power without the assumption of normality in the sampling distribution, making it the preferable method for testing indirect effects [32]. This method takes a random sample of size  $n$  without replacement from the sample then estimates the indirect effect in this “resample” to be repeated a total of  $k$  times [33]. Hayes recommends  $k$  equal at least 5,000. Parameter estimates and CIs of the total and indirect effects were generated based on 10,000 random samples with a 95% confidence level. Mediation was demonstrated if the CI did not contain zero.

All analyses were performed using SPSS®, version 22.0 statistical software.

## **Results**

Study participants included two groups, 1) 222 BCS and 2) 222 partners of the BCS. At the time of data collection, BCS ranged 30 to 54 years of age, and partners ranged 30 to 75 years of age. While inclusion criteria required BCS to be 3 to 8 years post diagnosis and treatment at enrollment, some participants ( $n=5$ ) were 9 years post diagnosis by the time of data collection. See table 1 for complete demographic information for the samples.

Scores on the overall fear index of the CARS ranged from 4 to 24 for both BCS and partners with good variability of low, moderate, and high scores, as defined in Vickberg’s original scoring [34]. Also, scores on the Lepore Social Constraints Scale ranged from 14 to 55 for BCS with a total of 80.7% of BCS and 78.8% of partners reporting constraints. Table 2 presents results for all scales.

### **Mediation Analysis for BCS**

For BCS, only current age was significantly correlated with FOR ( $r = -.239$ ,  $p = .01$ ); thus, age was the only demographic variable entered in the analysis. BCS who reported greater constraints reported higher scores for cognitive processing than those who reported fewer constraints (path  $a=0.672$ ), and in turn reported more FOR (path  $b=0.310$ ). Social constraints

demonstrated a significant indirect effect on FOR through the mechanism of cognitive processing (point estimate of indirect effect = 0.208, 95% bootstrap CI = 0.144 to 0.294). After accounting for the mediation effect of cognitive processing, there was no effect of social constraints on FOR (direct effect = 0.075,  $p = 0.108$ , 95% CI = -0.016 to 0.166). Therefore, as hypothesized, cognitive processing mediated the effect of social constraint on FOR.

### **Mediation Analysis for Partners**

For partners, only years of education correlated with FOR ( $r = -.164$ ,  $p = .015$ ) and was, therefore, the only variable entered in the mediation analysis for partners. Partners who reported greater constraints reported higher scores for cognitive processing than those who reported fewer constraints ( $a = 0.631$ ) and, in turn reported more FOR ( $b = 0.292$ ). Social constraints demonstrated a significant indirect effect on FOR through the mechanism of cognitive processing (point estimate of indirect effect = 0.184, 95% bootstrap CI = 0.119 to 0.271). After accounting for this mechanism, there was no effect of social constraints on FOR (direct effect = 0.038,  $p = 0.469$ , 95% CI = -0.066 to 0.142). Therefore, as hypothesized, cognitive processing mediated the effect of social constraints on FOR.

### **Discussion**

This study was the first to examine whether the Social Cognitive Processing Theory could be used to predict FOR in a sample that uniquely included young, long-term BCS and their partners. As hypothesized, cognitive processing mediated the relationship between social constraints and FOR in young, long-term BCS and separately in their partners. When BCS or their partners feel constrained in talking about breast cancer, they are unable to process the trauma caused by breast cancer [17, 18], resulting in increased FOR. These results are consistent with previous research testing the SCPT [17, 18, 24, 25]. This previous work found that if BCS felt constrained in their communication, then they were unable to cognitively process a trauma such as cancer, resulting in higher levels of distress than in those who did not experience social constraints. Likewise, partners who experienced social constraints from the survivors reported more cancer-related intrusive thoughts and more distress than partners who did not experience social constraints [22].

Our sample included young BCS who had been diagnosed 3-8 years prior at age 45 years or younger, and their partners. As women are typically diagnosed with breast cancer at a later age [10], this sample represents a minority of BCS who are not often studied but who typically report greater FOR [11]. Champion et al. (2014) found that among long-term BCS, young BCS compared to their older counterparts reported greater FOR, with younger BCS scoring nearly one standard deviation higher than older survivors [35]. Additionally, this unique data set allowed us to compare results between BCS and their partners using identical measures and methods. Because BCS and their partners were provided the same questionnaires, we were able to mirror the analyses between BCS and partners in order to see if cognitive processing differentially mediates the relationship between social constraints and FOR, and it did not. These results support inclusion of both BCS and partners in interventions to decrease social constraints because both parties experience social constraints and resulting FOR.

Neither of the demographic variables entered in the models- current age for survivors and years of education for partners- were significant in the mediation models. We found no



difference in FOR scores relative to time since diagnosis, which is consistent with a recent review reporting no relationship between time since diagnosis and FOR [8].

Scores on the CARS varied, with a large proportion of BCS (52.3%) reporting moderate-to-high FOR. This falls within the range of scores reported in other studies [4, 9] and supports the idea that FOR does not decrease with the passage of time [8]. In developing the CARS, Vickberg (2003) sampled women 1-7 years after treatment (mean of 3 years) and found 55% reported moderate-to-high FOR, consistent with our study [4]. Women in both samples were considered disease free, yet were still reporting notable levels of FOR. The majority of partners in our sample (53.6%) also reported moderate-to-high FOR. The similarity in FOR scores between BCS and partners in our study supports previous research that survivor and partner levels of FOR are comparable [14, 36]. Family caregivers—including partners/husbands—sometimes report higher levels of FOR than BCS [14], suggesting partners need to be offered supportive care services and included in interventions to reduce FOR.

The bivariate relationships between FOR and social constraints, as well as FOR and cognitive processing were strong for both BCS and partners in this sample. Other investigators have also found significant relationships between fear of recurrence and intrusive thoughts, cognitive avoidance, and social constraints [13, 24, 26]. However, without a theoretical model and mediation analyses, the story is incomplete. This analysis identified a strong mediator—cognitive processing—that can be used to frame an intervention to reduce social constraints between BCS and their partners. Past research has found FOR to be most problematic in younger BCS [11], but has failed to identify whether the same process occurs in partners of young BCS. Our analyses confirm that BCS and their partners frequently suffer from FOR and suggest that intervening on social constraints within the dyad might effectively reduce this understandable fear for both.

## **Conclusion**

Results from these analyses provide important information about predictors of FOR that can be used in the development of interventions to help BCS and their partners cope more effectively with one of the most common, lingering, and disruptive concerns after breast cancer diagnosis and treatment. Partners experienced similar levels of FOR as their loved one with breast cancer in the present study, a comparison that has been neglected in most studies. Including partners in analyses regarding social constraints is essential because constraints involve both people in the relationship. We found the same underlying relationships in both BCS and partners, which supports the use of a couple's intervention.

## **Limitations**

While this study provided the unique opportunity to explore the relationship between FOR and other variables using SCPT in long-term BCS and their partners, there are several limitations. First, the data from this study are cross-sectional under a non-experimental design, limiting our ability to draw causal inferences. Second, it is possible that other unmeasured variables help to explain the relationships. Third, while the majority of demographic variables previously reported did not impact levels of FOR, it is important to note our sample differed

from that of the general population. The sample in this study was mostly Caucasian and highly educated, with incomes higher than the general population, and may not be a representative sample of the breast cancer population. For these reasons, caution should be used when applying these findings to the larger breast cancer population.

### **Implications for Practice and Future Research**

Both BCS and their partners must process the trauma of breast cancer and most deal with FOR throughout survivorship. This study provided a framework through which future research can target constructs to develop and test interventions to decrease FOR. Interventions to reduce social constraints and promote open communication about breast cancer within the context of partnered relationships may enhance cognitive processing, ultimately decreasing fear of a breast cancer recurrence. One intervention that holds promise is Emotionally Focused Therapy (EFT), a structured intervention for couples grounded in attachment theory [37]. EFT focuses on intrapersonal (i.e., how partners process their own emotional experiences) and interpersonal processes (i.e., how partners respond to each other's emotions), which may help reduce the social constraints that inhibit effective cognitive and emotional processing of cancer stress for many couples. EFT is well established in non-cancer populations [38], and produced significant and sustained improvements in marital functioning among adults with cancer and their partners in a recent pilot study [39].

Although the results of the present analyses clearly indicate the appropriateness of SCPT in studying FOR, more research is needed to support these results. Future studies should track couples longitudinally to provide the opportunity to examine temporal relationships between social constraints, cognitive processing, and FOR. Additionally, sampling ethnically and economically diverse groups is necessary to determine if the SCPT has utility predicting FOR in the larger BCS population.

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Table a. Demographic Information for BCS and Partners

Variable	Survivors ( <i>n</i> =222)	Partners ( <i>n</i> =222)	
Race, No. (%)			
Caucasian	208 (93.7)	205 (92.3)	
Black or African American	5 (2.3)	7 (3.2)	
Asian	2 (0.9)	2 (0.9)	
Other	7 (3.2)	8 (3.7)	
Education (yrs), mean ( <i>SD</i> )	14.93 (2.5)	14.92 (2.6)	
Income, No. of Dyads (%)			
<=\$50,000	30 (13.5)		
>\$50,000 and <=\$100,000	109 (49.1)		
>\$100,000	83 (37.4)		
Religious affiliation, No. (%)			
Christian	194 (87.4)	185 (83.4)	
Jewish	6 (2.7)	8 (3.6)	
Other	3 (1.4)	3 (1.4)	
No religious affiliation	17 (7.7)	25 (11.3)	
Current age, mean ( <i>SD</i> )	45.35 (4.7)	47.98 (7.2)	
Current age range (years)	30-54	30-75	
Time Since Diagnosis, Years ( <i>SD</i> )	5.83 (1.51)		
Number of comorbidities for BCS/Chronic Conditions for Partners No. (%)			
0	89 (40.1)	76 (34.2)	

1	58 (26.1)	71 (32)	
2	33 (14.9)	45 (20.3)	
$\geq 3$	40 (18.9)	30 (13.5)	

Table b. Mean Scores, Standard Deviation, and Range of All Scales for BCS and Partners as well as Pearson Correlation Coefficients for BCS and Partner Scores

Measure	Mean (SD), Range Survivors	Mean (SD), Range Partners	Pearson Correlation Coefficients
Lepore Social Constraints Scale	20.947 (7.213), 14-55	20.331 (6.336), 14-40	.163*
Intrusive Thoughts (IES)	4.92 (5.55), 0-30	4.92 (5.18) 0-22	.168*
Cognitive Avoidance (IES)	4.91 (5.04), 0-23	3.69 (4.03), 0-23	.220**
Combined Intrusion and Avoidance subscales	10.78 (9.49), 0-46	8.61 (8.35), 0-37	.207**
Concerns About Recurrence Scale	12.548 (5.380), 4-24	11.794 (5.015), 4-24	.196*

\* Pearson correlation coefficient significant  $p < .05$

\*\* Pearson correlation coefficient significant  $p < .001$



Table c. Model Coefficients for BCS and Partners.

		<b>Survivors</b>					
		<u>M (Cognitive Processing)</u>			<u>Y (FOR)</u>		
		Coeff	SE	<i>p</i>	Coeff.	SE	<i>p</i>
Antecedent X (Social Constraints)	<i>a</i>	.672	.078	<.001	<i>c'</i>	.075	.046 .108
)							
M (Cognitive Processing)		-	-	-	<i>b</i>	.310	.035 <.001
Constant	<i>i'</i>	-	1.718	.258	<i>i''</i>	12.761	3.060 <.001
		3.240					
R <sup>2</sup> =.258				R <sup>2</sup> =.401			
F(1, 215)= 74.72, <i>p</i> <.001				F(3, 213)= 47.541, <i>p</i> <.001			
		<b>Partners</b>					
		<u>M (Cognitive Processing)</u>			<u>Y (FOR)</u>		
		Coeff.	SE	<i>p</i>	Coeff.	SE	<i>p</i>
Antecedent X (Social Constraints)	<i>a</i>	.631	.079	<.001	<i>c'</i>	.038	.053 .469
)							
M (Cognitive Processing)		-	-	-	<i>b</i>	.292	.040 <.001
Constant	<i>i'</i>	-4.280	1.665	.011	<i>i''</i>	11.448	2.08 <.001
		1					
R <sup>2</sup> =.229				R <sup>2</sup> =.280			
F(1, 217)= 64.498, <i>p</i> <.001				F(3, 215)= 27.917, <i>p</i> <.001			