

**CONSTRUCT VALIDITY OF FEAR OF RECURRENCE AMONG BREAST  
CANCER SURVIVORS**

by

Stefanie T. LoSavio

A dissertation submitted to the Faculty of the University of Delaware in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Psychology

Summer 2015

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## **ABSTRACT**

Advancements in cancer detection and treatment have improved the life expectancy of today's cancer patients. With patients living longer, many are now facing the challenges of survivorship. One of the most commonly reported problems among cancer survivors is fear of recurrence. Despite a recent proliferation of literature in the area of fear of recurrence, little theoretical and empirical work has been conducted to define and establish the validity of this important construct. To address this gap in the literature, we proposed and tested a cognitive-emotional theory of fear of recurrence. We then evaluated the convergent, discriminant, and concurrent validity of the theory-consistent items. Three hundred early stage breast cancer survivors completed measures of fear of recurrence, cancer-relevant behavioral outcomes (e.g., health care utilization, functional impairment), and other theoretically-related but distinct constructs (e.g., uncertainty intolerance, general health anxiety). We employed sophisticated structural equation modeling techniques to test our theory of fear of recurrence and evaluate its construct validity. Overall, we found support for our hypothesis that fear of recurrence is a unique construct with predictive power. We hope that findings from this study will expand the theoretical basis for fear of recurrence and serve as a foundation for continued research on this important construct.

## **Chapter 1**

### **INTRODUCTION**

According to the American Cancer Society (2014), a cancer survivor is any individual diagnosed with cancer, from the time of diagnosis until the end of his or her life. Advancements in cancer treatments have improved the life expectancy for today's cancer patients, leading to significant increases in the number of cancer survivors, recently estimated to be 14.5 million people within the United States (American Cancer Society, 2014). Breast cancer survivors make up the highest proportion of these cancer survivors (22% of all cancer survivors; 41% of all female cancer survivors; American Cancer Society, 2014). As of 2014, there were more than 3.1 million women with a history of invasive breast cancer in the United States (American Cancer Society, 2014). The 5-year relative survival rate for female breast cancer survivors has improved in recent years, from 75% between 1975 and 1977 to 90% for 2001 to 2007, due largely to improvements in detection and treatment (American Cancer Society, 2014). Although cancer patients are living longer, many continue to deal with the long-term physical and psychological consequences of the illness.

Perhaps surprisingly, the completion of cancer treatment and the transition from cancer patient to survivor has been identified as a period of continued stress.

One physician cancer survivor described her own post-treatment experience: “I thought I would feel happy about finally reaching the end of treatment... Instead of joyous, I felt lonely, abandoned, and terrified... I have now finished surgery, chemotherapy, radiation, and reconstruction; I’m done, according to the medical profession. But I don’t really *feel* done. I think we survivors are never truly done. We just move from the quantifiable, treatable disease to the immeasurable uncertainty of survivorship” (McKinley, 2000, p. 479).

Psycho-oncologists argue that some of the difficulties faced by cancer survivors during this transition are due to myths or unrealistic expectations surrounding treatment completion (Stanton et al., 2005). First, some may believe that the end of treatment should be a time for celebration; however, for many, the end of treatment is the beginning of processing a significant life event. Additionally, some may feel more comfortable with the active treatment period, which is characterized by more perceived control and focus on action. Thus, the end of treatment may be characterized more by a sense of "What now?" (Stanton et al., 2005). In line with this perspective, McKinley (2000) described, “Now that my cancer treatment is done and my disease is no longer visible to my physicians and their diagnostic tests, I have begun to deal with the weight of its uncertain return” (p. 479).

An additional myth is that survivors should recover and return to their pre-cancer functioning immediately after the completion of treatment (Stanton et al., 2005). Physical changes alone may serve as a reminder of how the individual has changed.

Finally, another myth is that the survivor no longer needs support once treatment is over. Whereas the treatment phase usually involves a great deal of support from both the medical team and the individual's personal support network, many cancer survivors describe a sharp decrease in their available support after treatment, which may further exacerbate distress (Stanton et al., 2005). As McKinley (2000) aptly described, “Being in the midst of active treatment means being seen regularly by a nurse or a physician—being *cared* for. As I got up off that radiation table for the last time and walked away, I found myself alone with a cancer ghost who would not let me forget where I had been or allow me to freely choose where I might be going” (p. 479).

It is clear that the end of treatment is merely the beginning of a new phase of the cancer experience—survivorship. Cancer survivors cope with many potential challenges as they adjust to life post-treatment. As underscored by some of the aforementioned survivorship myths, the end of treatment may be characterized by a great deal of uncertainty and leave survivors feeling changed in ways they have not yet completely processed. Given such uncertainty about cancer and its potential return, not surprisingly, one of the most common concerns reported by cancer survivors, even long after treatment ends and among those considered “cancer-free,” is fear of recurrence (e.g., Koch, Jansen, Brenner, & Arndt, 2013; Siegel et al., 2012).

### **1.1 Fear of Recurrence**

The topic of fear of recurrence has gained increasing research attention over recent years. To illustrate, an examination of PsycINFO records reveals that, when

searching for “fear of recurrence” and “cancer” or “fear of cancer recurrence,” there were just 17 articles published before 2000. By contrast, there were 178 new articles since 2000, more than half of which were published in the last five years. Likewise, an examination of MEDLINE records reveals increasing rates of publication over the last few decades with 27 articles on the topic prior to 1990, 69 articles between 1990 and 2000, 187 between 2000 and 2010, and 239 since 2010. Fear of recurrence has also been gaining attention in the popular media, as evidenced by a recent article on the New York Times *Well* website, “Anxiety Lingers Long After Cancer” (Hoffman, 2013).

Despite increasing attention to fear of recurrence, some have pointed out that research on the topic has expanded haphazardly (Simard et al., 2013). First, there is no one widely accepted and consensual operational definition of the construct (Simard et al. 2013; Thewes et al., 2012). Some have described fear of recurrence as "waiting for the other shoe to drop," citing survivor descriptions of the experience: “The ache and pain that I have—like my thumb getting locked—I think, ‘Oh my God—cancer of the bone.’ You think that every single day” and ““You just have that uncertainty. Ok my treatment is over with, now what? What’s going to prevent the breast cancer from coming back?”” (Waldrop, O'Connor, & Trabold, 2011, p. 467). Others have characterized fear of recurrence as a "sword of Damocles," a constant threat hanging over the heads of survivors, causing fear and detracting from enjoyment of life (e.g., Cesario, Nelson, Broxon, & Cesario, 2010). Two of the more commonly cited definitions of fear of recurrence in the literature include "the degree of concern

reported by subjects about the chances of cancer returning at a future time" (Northouse, 1981, p. 214) and "the fear that cancer could return or progress in the same place or in another part of the body" (Vickberg, 2003, p. 18).

Based on these broad definitions, many researchers have documented high prevalence rates of (at least some degree of) concern about recurrence. For example, in a large sample of cancer survivors of various disease sites one year post-diagnosis, Baker, Denniston, Smith, and West (2005) found that the majority of cancer survivors endorsed feeling "concerned about disease recurrence" and "fearful about their future" (p. 2571). Further, being "fearful my illness will return" was either the first or second highest rated problem among cancer survivors across each of the four most common disease sites (i.e., breast, prostate, colorectal, and lung, second only to sexual dysfunction for prostate cancer and fatigue/loss of strength for breast and lung cancer; Baker et al., 2005). Given that researchers have documented high prevalence rates of "concerns" about the possibility of recurrence, broadly conceived, this raises the question of whether fear of recurrence is normative or whether, at certain levels, it is associated with negative outcomes like functional impairment. Although there is some agreement that fear of recurrence exists on a continuum from normal to extreme, there is no consensus about a clinical level of fear of recurrence (Simard et al., 2013).

Another issue is that the working definitions described above provide little information about specific symptoms or features of fear of recurrence, making it difficult to discern fear of recurrence from other similar constructs, such as general health anxiety. Some researchers have also included in their definitions of fear of

recurrence features that may best be described as antecedents (e.g., triggers such as physical symptoms) or consequences of fear of recurrence (e.g., functional impairment, reassurance-seeking, etc.) Therefore, clear specification of the specific features of fear of recurrence would be important for conceptual clarity as research on this important construct continues to grow.

Additionally, the lack of definitional clarity has resulted in the development and use of many measurement scales to operationalize fear of recurrence including multi-item scales, single-item scales, and subscales part of broader measures of constructs such as cancer-specific quality of life. The range of assessment tools used in fear of recurrence research likely contributes to the wide range of prevalence rates reported in the literature (e.g., 5-89%; Simard et al., 2013; Thewes et al., 2012). As noted in a recent review of fear of recurrence measures, “the lack of consensus on definition, a gold-standard [fear of recurrence] measurement tool and established cut-off scores for clinically significant [fear of recurrence] all hinder studies about this phenomenon” (Thewes et al., 2012, p. 571).

Ideally, a clearly-operationalized fear of recurrence construct would be predictive of important behavioral outcomes relevant for cancer survivors. For example, elevated fear of recurrence may lead some survivors to be vigilant about their health and diagnostic status, contributing to increased health care utilization. Further, a clearly-defined and unique construct should be able to predict relevant behavioral outcomes better than any single measure of a different construct and as well as and more efficiently than the combination of measures of multiple other

constructs. For example, fear of recurrence should predict relevant outcomes for cancer survivors, such as frequent visits and phone calls to oncology providers' offices for reassurance, better than general anxiety.

In a recent review paper, psycho-oncologists recommended that, for research on fear of recurrence to advance, researchers must identify the specific features of fear of recurrence, agree upon a definition of the construct, and propose and evaluate a theoretical model (Simard et al., 2013). Our primary goal in undertaking this study was to respond to this call. We hoped to advance knowledge of the construct of fear of recurrence and address the weaknesses noted above by utilizing empirical data and sophisticated statistical methods. We proposed and tested a theory-based conceptualization of fear of recurrence including identifying the hypothesized defining features of the construct and engaging in a series of steps to add to the construct validation of fear of recurrence (i.e., establishing it as a distinct construct with unique predictive power).

In order to develop a clearer conceptualization of fear of cancer recurrence, our first task was to propose and evaluate a comprehensive theory of the construct. Based on previous theories and research findings, we proposed and evaluated a definition of fear of recurrence, including specification of the construct's primary features (detailed below). We outlined what fear of recurrence is, as well as what the antecedents and consequences of fear of recurrence are. We also identified several outcomes that should be associated with fear of recurrence and tested our hypotheses that fear of recurrence is meaningfully related to these important outcomes. To do so, we used

items from existing measures of fear of recurrence, plus additional, theory-related items, and assessed their ability to cohere as a unidimensional construct and predict relevant outcomes. Then, to add to the construct validation of fear of recurrence, we assessed whether fear of recurrence can be predict outcomes as well as or better than rival constructs.

We also tested predictions about the aspects of fear of recurrence that are common to other constructs and those that are unique. We hoped that this work would not only build a stronger foundation upon which researchers can continue study of fear of recurrence, but that it would also further demonstrate that fear of recurrence is an independent construct that is compelling and worthy of further study. For example, we proposed that fear of recurrence shares many qualities with anxiety and anxiety-related disorders, yet it is also unique because, in some cases, it may involve distressing concern about *realistic* outcomes (i.e., threat perception may not be distorted).

### **1.1.1 Existing Theories Relevant to Fear of Recurrence**

Despite an expanding body of literature on fear of recurrence, there has been little published work proposing a theoretical framework for this construct. Two notable exceptions include a cognitive-behavioral model (Lee-Jones, Humpris, Dixon, & Hatcher, 1997; Leventhal, Diefenbach, & Leventhal, 1992) and the extended parallel process model (McGinty et al., 2012) of fear of recurrence.

### **1.1.1.1 A Cognitive-Behavioral Model of Fear of Recurrence**

Lee-Jones et al. (1997) proposed a theoretical formulation of fear of cancer recurrence that includes cognitive, emotional, and behavioral components, based on earlier work by Leventhal et al. (1992). They suggested that each individual possesses their own illness representation—a mental model of illness, which may be based upon personal experiences, myths, the media, personality, and previous coping methods (Lee-Jones et al., 1997). For example, one might have a representation of cancer in which the disease is viewed as painful and resulting in imminent death. Variations in illness representations explain why people may respond differently to cancer diagnosis and why some survivors may experience more fear of recurrence than others (Lee-Jones et al., 1997). Lee-Jones et al. (1997) proposed that those who have higher fear of recurrence are more likely to believe cancer to be chronic with negative, uncontrollable consequences.

Lee-Jones et al. (1997) also suggested that cues (internal or external) activate cognitive responses. For example, bodily sensations may remind a survivor of cancer or make her think that her cancer is back. External cues, such as medical appointments or other reminders of cancer, may also incite worrying thoughts about recurrence. Cognitive responses might include "(worrying) thoughts about recurrence, doubts about the eradication of the cancer, and concerns that the doctor is not checking carefully enough" (Lee-Jones et al., 1997, p. 101). These cognitions are based upon the individual's illness representation, knowledge, past experience, beliefs, and perception of personal recurrence risk. In line with cognitive-behavior theory, Lee-

Jones et al. (1997) argued that these cognitions will likely be accompanied by threat-related emotions. Emotions likely to be activated include anxiety, fear, dread, or even remorse (e.g., about not pursuing more aggressive treatment; Lee-Jones et al., 1997). The emotional response may lead to further changes in behavior. Likely behavioral responses include self-checking behavior, seeking professional advice and reassurance, and limiting one's planning for the future (i.e., reduction in forward action). Furthermore, physiological symptoms of anxiety, especially when coupled with hypervigilance to bodily sensations, are likely to be misinterpreted as symptoms of cancer, leading to more concern about recurrence, maintaining and/or reinforcing this cognitive-behavioral system (Lee-Jones et al., 1997).

#### **1.1.1.2 The Extended Parallel Process Model**

McGinty et al. (2012) proposed another relevant theoretical framework for studying fear of recurrence: the extended parallel process model (EPPM; Witte, 1992). The EPPM focuses on threat and coping appraisal. According to McGinty et al. (2012), threat appraisal includes two components: "vulnerability (the perceived personal risk that the health threat will occur) and severity (the inherent dangerousness of the health threat if it were to occur)" (p. 204). By contrast, coping appraisal includes "the combination of response efficacy (the expectation that a given behavior will successfully reduce the health threat) and self-efficacy (the belief that one can successfully perform a given behavior)" (p. 204). According to this model, whether a person experiences elevated fear of recurrence is determined by the interaction of their threat and coping appraisals. Theoretically, someone with a low threat appraisal and a

high coping appraisal would experience minimal fear, whereas someone with the opposite pattern (i.e., high threat appraisal, low coping appraisal) would experience the most fear of recurrence.

In a study testing the EPPM of fear of recurrence, McGinty et al. (2012) assessed 155 Stage I and II breast cancer survivors 6-24 months post-treatment with no history of other cancers and no recurrence since the original diagnosis. As hypothesized, they found that the interaction between threat appraisal and coping appraisal predicted fear of recurrence, with survivors reporting higher levels of threat appraisal and lower levels of coping appraisal reporting the most fear of recurrence. The authors suggested that this combination of high threat appraisal and low coping appraisal reflects the perception that there is a high likelihood of a health threat and little that can be done to reduce one's risk. Fear of recurrence was also related to greater threat appraisal overall, which accounted for 30% of the variance in fear of recurrence, whereas coping appraisal alone did not correlate with fear of recurrence; instead, it moderated the effects of threat appraisal on fear, consistent with the EPPM (McGinty et al., 2012).

Both the cognitive-behavioral model and the EPPM include elements relevant for a comprehensive theory of fear of recurrence. However, one issue with the cognitive-behavioral model is that it does not clearly specify which features are part of fear of recurrence proper, and which features are antecedents and consequences of fear of recurrence. For example, is being triggered by cues part of fear of recurrence? Are behaviors like checking oneself for signs and symptoms of cancer part of fear of

recurrence? The definition of fear of recurrence proposed in the present study separates fear of recurrence from its antecedents and consequences. Furthermore, the cognitive-behavioral model of fear of recurrence has yet to be tested (Simard et al., 2013).

The EPPM also highlights an interesting aspect of fear of recurrence—a perceived discrepancy between threat and coping appraisal. The model’s authors conceptualize coping appraisal as the belief that taking certain measures can reduce the likelihood of cancer recurrence and the belief that one has the ability to carry out such measures; however, it is possible to more broadly conceptualize coping appraisal. For example, some anxiety theories highlight the importance of the individual’s perception that he or she could cope with the feared outcome if it did in fact occur (e.g., Beck, Emery, & Greenberg, 1985). One’s perception of their ability to cope with a negative outcome is particularly relevant in this area because recurrence is indeed a possibility, and survivors may need to consider their ability to cope with recurrence if it did in fact occur (e.g., do they feel like they can handle another round of chemotherapy?). Furthermore, for some survivors, a recurrence of cancer might signify that the cancer is no longer curable and require coping with that possibility. Thus, we were interested in evaluating a more inclusive definition of coping appraisal in our model. Furthermore, a discrepancy between threat appraisal (one’s personal perception of risk of recurrence) and an objective estimate of risk (e.g., as determined on the basis of objective clinical characteristics) is likely another type of discrepancy that may be relevant for fear of recurrence. Overestimation of personal risk may help

explain why a survivor with a favorable prognosis may still experience high distress (e.g., Rabin, Leventhal, & Goodin, 2004). Therefore, we were interested in examining this additional type of discrepancy in our fear of recurrence model.

#### **1.1.1.3 Parallels with Anxiety Theory**

Both the Lee-Jones et al. (1997) and McGinty et al. (2012) models are consistent with theories of anxiety. One commonly cited anxiety theory is that of a fear structure—a cognitive set containing interrelated stimulus, response, and meaning information that becomes activated by information in the environment (Foa & Kozak, 1986). The cognitive-behavioral model is consistent with this theory in that Lee-Jones et al. (1997) suggested a number of cognitive, emotional, and behavioral components that are activated by the perception of threat. The EPPM is also consistent with theories of anxiety. Namely, many anxiety theorists have posited that anxious individuals overestimate the degree of harm associated with feared stimuli (corresponding to high threat appraisal) and underestimate their abilities to cope with the dreaded outcome (corresponding to low coping appraisal; e.g., American Psychiatric Association [APA], 2000). Overall, both the cognitive-behavior model and EPPM are useful organizing theories for understanding fear of recurrence that are also anxiety theory-consistent.

#### **1.1.1.4 A Departure from Anxiety Theory**

In their anxiety theory, Foa and Kozak (1986) differentiated normal fear structures from pathological fear structures. Normal fear structures are adaptive, and associations between stimulus, response, and meaning representations accurately

reflect reality. Therefore, when true danger activates a normal fear structure, the individual experiences fear and reacts to avoid real harm. Pathological fear structures, by comparison, contain associations among representations that do not accurately reflect reality (e.g., perceiving threats of danger in veridically safe situations) and lead to excessive behavioral responding (e.g., avoidance of veridically safe situations; Foa, Huppert, & Cahill, 2006).

Conceptualizing fear of recurrence as an anxiety construct, the feared outcome would be a future instance of cancer (diagnosis of the same or a new cancer in the same or a different place in the body). What is unique about fear of recurrence, however, is that the likelihood of this feared outcome is not necessarily a distortion of reality. Indeed, women who have previously been diagnosed with breast cancer are in fact at a greater risk of developing breast cancer again as compared to women who have not been previously diagnosed (e.g., Nielsen, Nordestgaard, & Bojesen, 2012). Thus, a key feature that sets fear of recurrence apart from anxiety and anxiety-related disorders is that there is, in some cases, a real threat, and thus, fear of recurrence may not completely fit with anxiety disorder theories of pathological distortion of reality.

### **1.1.2 An Integrated Theory of Fear of Recurrence**

Based on previous theory and research, including both the cognitive-behavioral and extended parallel process models of fear of recurrence, we propose here an integrated, cognitive-emotional theory of fear of recurrence. We propose that fear of recurrence is a *future-oriented*, anxiety state. In line with Lee-Jones et al. (1997), we propose that fear of recurrence involves *cognitive* (e.g., worry about recurrence, risk

perception) and *emotional* (e.g., fear) components. We also suggest that one of the cognitive components of fear of recurrence is a *discrepancy*, either between one's subjective perception of risk of recurrence and an objective estimate of risk or, in line with McGinty et al. (2012), between one's subjective perception of risk and one's perception of coping self-efficacy, that in turn causes distress. We suggest that cognitions in fear of recurrence are specifically *future-oriented* (e.g., "What if I get cancer again?"), and not concerned principally with past experiences with cancer. One of our aims was to clearly specify what is fear of recurrence versus an antecedent or consequence of fear of recurrence. Therefore, we propose that cognitive and emotional components of fear of recurrence may be activated by internal or external cues (e.g., physical sensations, encounters with the medical system) that lead to behavioral outcomes (e.g., reassurance-seeking, avoidance); however, such antecedents and consequences are not part of fear of recurrence itself.

As detailed below, based on this theory of fear of recurrence, we expected fear of recurrence to be associated with a number of relevant behavioral outcomes such as medical and mental health care utilization, physical self-examination, functional impairment, and forward movement in life. Also detailed later, we expected fear of recurrence to demonstrate convergence with other clinical constructs, but to be distinct in key conceptual ways.

## **1.2 Behavioral Outcomes related to Fear of Recurrence**

We have identified several behavioral indicators that should theoretically coincide with elevated levels of fear of recurrence. These include 1) health care

utilization, 2) mental health treatment, 3) physical self-examination, 4) functional impairment, and 5) goal-striving. These indicators can serve several purposes. First, they can help validate a theory of fear of recurrence by demonstrating that theory-based items are strongly associated with behavioral outcomes relevant for cancer survivors. These indicators can also be used to determine the conditions under which fear of recurrence become unhealthy/problematic. For example, fear of recurrence may have a linear relationship with negative behavioral outcomes (e.g., negative outcomes occurring across the full range of fear of recurrence severity), there may be a clinical cut-point in fear of recurrence symptoms at which these negative behavioral outcomes become apparent, or the relationship between fear of recurrence and behavioral outcomes may be moderated by other important factors, such as how an individual relates to or responds to their thoughts and feelings. Each of these possibilities will be explored. Finally, these behavioral indicators can be used to evaluate whether a measure of fear of recurrence predicts meaningful behavioral outcomes *as well as or better than* measures of other constructs, as a means of demonstrating that fear of recurrence has unique predictive power.

### **1.2.1 Health Care Utilization**

The American Society of Clinical Oncology recommends that cancer survivors visit their doctor every 3-6 months for the first three years after treatment, every 6-12 months for years four and five, and annually thereafter (Khatchernessian et al., 2013). Those higher in fear of recurrence may utilize the health care system in an atypical manner. Individuals high in fear of recurrence may exhibit greater utilization of the

health care system given more concerns about potential health threats and more attention paid to physical symptoms. Thus, those high in fear of recurrence might have more non-routine visits to their oncologist or primary care physician or make frequent phone calls to their doctor's office inquiring about symptoms. In one study of long-term testicular cancer survivors, fear of recurrence, assessed with a one-item question, was associated with having seen a general practitioner in the last year (Skaali et al., 2009). Additionally, in a sample of mixed disease site cancer survivors, those higher in fear of recurrence were more likely to call or visit their doctor than those lower in fear of recurrence (Cannon, Darrington, Reed, & Loberiza, 2011).

On the other hand, it is also possible that individuals with fear of recurrence will be avoidant of medical encounters (e.g., Mehnert et al., 2009). In general, anxiety disorders are characterized by avoidance. Thus, someone high in fear of recurrence might attempt to avoid reminders of their cancer in order to limit their distress. In one study, researchers found that patient-provider communication positively and directly influenced the number of troublesome thoughts of recurrence; as the amount of communication with providers increased, so did a woman's thoughts about recurrence (Clayton et al., 2006). Thus, individuals may avoid interfacing with the medical system to limit thoughts of recurrence.

Taken together then, the relationship between fear of recurrence and health care utilization may be linear (e.g., increasing utilization with increasing fear of recurrence), non-linear (e.g., higher levels of utilization as fear of recurrence moves from low to moderate levels but lower levels of utilization at high levels of fear of fear

of recurrence), or bi-modal (e.g., two unique fear of recurrence profiles—one avoidant, and one medical reassurance-seeking). In our analyses, we will assess the relationship between fear of recurrence and health care utilization, including assessing for each of these potential patterns of relations.

### **1.2.2 Mental Health Treatment**

We would also expect that those high in fear of recurrence would be more likely to seek out mental health treatment such as counseling or psychotropic medications. Given that fear of recurrence is distressing, it might prompt individuals to seek out a means of alleviating their distress. Indeed, fear of recurrence was associated with mental health treatment (i.e., seeing a psychiatrist or psychologist) and use of psychotropic medication (i.e., anxiolytics, hypnotics, and antidepressants) in the aforementioned sample of long-term testicular cancer survivors (Skaali et al., 2009). However, it is possible that some survivors high in fear of recurrence might be avoidant of both mental health services and participation in research. Another study showed that, across various disease sites, cancer survivors were more likely to have an anxiety/adjustment/sleep disorder diagnosis than their cancer-free, matched counterparts, and breast cancer survivors had more outpatient visits with mental health providers than other cancer survivors and non-survivors; however, this study did not examine the relationship between mental health issues/service utilization and fear of recurrence specifically—only cancer survivorship status in general (Earle, Neville, & Fletcher, 2007).

### **1.2.3 Self-Examination**

The American Society of Clinical Oncology currently recommends monthly breast self-examinations following treatment of breast cancer (Khatcheressian et al., 2013). However, breast self-examination has been a source of controversy, and a number of organizations are placing less emphasis on formal breast self-examination practices for women overall (e.g., National Breast Cancer Coalition, 2011). While breast cancer survivors are instructed to be aware of major bodily changes, hypervigilance about bodily sensations and concerns about their meaning might lead some survivors to engage in excessive checking behavior including frequent self-examination of the breast or other areas of the body for signs and symptoms of cancer. This behavioral indicator would be consistent with Lee-Jones et al.'s (1997) cognitive-behavioral conceptualization of fear of recurrence. To our knowledge, no researchers have yet linked fear of recurrence and self-examination; however, some research on non-diagnosed women at a high risk of breast cancer suggests that greater worry was associated with more breast self-examination (e.g., McCaul et al., 1998; McCaul, Schroeder, & Reid, 1996), although there is some contradictory evidence from more recent research (e.g., Posluszny, McFeeley, Hall, & Baum, 2004).

### **1.2.4 Functional Impairment**

Those high in fear of recurrence may have difficulty continuing to engage normally in their routine activities and roles affecting their work and interpersonal relationships. Functional impairment is a hallmark feature of clinical disorders, broadly. Thus, functional impairment could serve as an important behavioral index of

disruptive levels of fear of recurrence. Much previous research on impairment associated with fear of recurrence has focused on emotional, physical, and cognitive functioning, as well as quality of life more broadly (e.g., Simard et al., 2013). However, some research suggests that fear of recurrence is associated with difficulties in social and role functioning (e.g., van den Beuken-van Everdingen et al., 2008). Additionally, in a recently developed fear of recurrence measure, the authors included functional impairment items as part of the scale, reflecting their belief that fear of recurrence is associated with functional impairment broadly, including interference with work, leisure, and social activities (Simard & Savard, 2009).

### **1.2.5 Goal-Striving**

Those high in fear of recurrence may have a sense of a foreshortened future, anticipating that they will be re-diagnosed and either die from cancer or have to undergo painful or life-interfering treatments. Thus, another potentially relevant behavioral index of fear of recurrence is decreased forward life movement, or, goal-striving. Those high in fear of recurrence might avoid pursuing valued goals (e.g., making major purchases such as a new home or new car, starting new relationships, etc.). To our knowledge, there has been no research examining the link between fear of recurrence and goal-striving.

### **1.2.6 Positive Health Changes**

Some researchers have proposed that fear of recurrence may have positive benefits, such as positive behavioral changes (see Park & Gaffey, 2007 for a review). Anxiety may facilitate motivation for change, such as improved eating habits, physical

activity, or building social support, all of which are known to reduce cancer recurrence or improve coping ability. Across a few different studies, intrusive thoughts, distress, somatic complaints, and cancer worry were related to making positive changes; however, in other studies, recurrence distress was not associated with positive change (Park & Gaffey, 2007). In an integrative review, Park and Gaffey (2007) identified psychosocial factors that might facilitate positive behavioral change after cancer diagnosis. They identified that social support may be helpful to making positive changes, especially exercise. Further, they identified that cancer-specific perceived control and self-efficacy beliefs among those who recognize the link between behavior change and decreased recurrence risk facilitate positive change. Finally, they observed that cancer-related distress, such as fear of recurrence, but not general distress, may facilitate positive change. Park and Gaffey (2007) highlighted, however, the many inconsistencies in the literature. Taken together, it appears that cancer-related distress can, in some cases, be a motivator of health behavior change. In the proposed study, we included items inquiring about positive changes since diagnosis to assess whether, and under what conditions, fear of recurrence might be associated with positive outcomes.

### **1.3 Constructs related to Fear of Recurrence**

A number of constructs likely overlap with fear of recurrence. We examined the relation between fear of recurrence and theoretically-related constructs, including other anxiety-related constructs (i.e., anxious apprehension, uncertainty intolerance, and anxious arousal), as well as multifaceted, clinical constructs (i.e., generalized

anxiety disorder [GAD], posttraumatic stress disorder [PTSD], and general health anxiety [illness anxiety disorder/somatic symptom disorder]). We also evaluated the predictive power of fear of recurrence over these other constructs.

### **1.3.1 Theoretically-related Anxiety Constructs**

We examined three anxiety-related constructs: anxious apprehension, uncertainty intolerance, and anxious arousal. We expected each of these constructs to be related to, but distinguishable from, fear of recurrence. Furthermore, we expected fear of recurrence to be able to predict behavioral outcomes *better* than any of these constructs individually, and we expect fear of recurrence to be able to predict behavioral outcomes *at least as well as*, and more efficiently than, these constructs combined.

#### **1.3.1.1 Anxious Apprehension**

Anxious apprehension refers to a trait-like tendency to worry excessively—“a future-oriented mood state in which one becomes ready or prepared to attempt to cope with upcoming negative events” (Brown, O’Leary, & Barlow, 2001, p.158). Not surprisingly, anxious apprehension is a hallmark of GAD (Barlow, 1988). Worry is considered a central feature of fear of recurrence, and, accordingly, various measures of anxiety have been linked to fear of recurrence with moderate- to large-size correlations (e.g., Deimling et al., 2006; Simard & Savard, 2009; Stanton et al., 2002).

#### **1.3.1.2 Uncertainty Intolerance**

A related construct is uncertainty intolerance, which refers to an individual's tendency to be intolerant of the notion that negative events may occur with no

definitive way of predicting or avoiding them (Ladouceur, Gosselin, & Dugas, 2000). In one recent study, researchers linked uncertainty intolerance to "cancer-related distress," as measured by the Impact of Events Scale in a sample of prostate cancer survivors 3-5 years post-treatment (Eisenberg et al., 2015). In another study sampling breast cancer patients one month following treatment, researchers found that intolerance of uncertainty was trending but non-significant as a predictor of cancer worry (Costa-Requina, Rodriguez, Fernandez, Palomera, & Gil, 2011). In another study, the association between uncertainty intolerance and health anxiety in a sample of breast cancer survivors was also approaching significance (Jones, Hadjistavropoulos, & Gullickson, 2014).

#### **1.3.1.3 Anxious Arousal**

Clark and Watson (1991) proposed a tripartite model of anxiety and depression which includes anxiety-specific symptoms, depression-specific symptoms, and a shared negative affect common factor of the two. Phenomenologically, the constructs of anxiety and depression are different (Watson et al., 1995). In spite of a theoretical distinction, these two constructs have been difficult to separate with most measures of depression or anxiety (Clark & Watson, 1991; Watson et al., 1995). Although depression and anxiety should be correlated to some extent, their overlap may be overestimated given common measurement strategies (Clark & Watson, 1991; Watson et al., 1995). They suggested a tripartite structure consisting of a general distress factor ("subjective distress" and "negative mood states, including fear, sadness, anger, guilt, scorn, and disgust;" often overlapping with anxiety and depression), an anxious

arousal factor (physiological hyperarousal; specific to anxiety), and an anhedonic depression factor (lack of positive affect; specific to depression; Watson et al., 1995, p. 4).

Thus, anxious arousal refers to that aspect of anxiety that is relatively independent of depression. It is characterized by “heightened physiological (autonomic) arousal, symptoms of which include racing heart, trembling, shortness of breath, dizziness,” as well as general heightened sensitivity to internal cues (Clark, Watson, & Mineka, 1994, p. 108). Panic disorder is characterized by anxious arousal (Clark et al., 1994). To our knowledge, no research has linked anxious arousal in particular to fear of recurrence, but several studies have demonstrated relations between fear of recurrence and anxiety in general (e.g., Deimling et al., 2006, Stanton et al., 2002). Characterizations of fear of recurrence seem to overlap with much of the general factor of negative affectivity, including worry. Thus, fear of recurrence will likely share some overlap with anxious arousal, again, in accordance with the Lee-Jones (1997) model, but perhaps not as much as general worry/anxious apprehension.

### **1.3.2 Multifaceted Clinical Constructs**

Given the commonality between anxiety processes and theories of fear of recurrence, we propose that the construct of fear of recurrence likely overlaps with some anxiety and anxiety-related disorders. We evaluated the possibility that fear of recurrence is similar to/has overlapping features with GAD, PTSD, and general health anxiety, but that it is distinct from these clinical constructs in critical ways.

### **1.3.2.1 Generalized Anxiety Disorder**

GAD involves excessive, difficult-to-control worry about multiple topics, as well as associated symptoms (e.g., restlessness, muscle tension, difficulty concentrating; APA, 2000). GAD is characterized by the perception “that the world is threatening and that one may not be able to cope with or control future negative events” (Barlow et al., 1996; Borkovec, 1994; as cited in Brown et al., 2001, p. 160). In GAD, the intensity, duration, or frequency of the worry is considered disproportionate to the likelihood or severity of the feared outcome (APA, 2000). Common worries experienced by individuals with GAD often include every day, routine life issues such as job responsibilities, finances, and health of family members (APA, 2000). What appears to distinguish GAD from other anxiety disorders is whether individuals worry excessively about minor matters (Barlow, 1988). Some have argued that GAD is akin to a personality trait, given its early onset (see Brown et al., 2001 for a review).

To our knowledge, there has been no research investigating the link between fear of recurrence and GAD; however, we would expect to find some association between these constructs. Namely, while fear of recurrence and GAD may have in common a general tendency to worry excessively, we expected that, in fear of recurrence, the worry would be focused primarily on the possibility of cancer returning, as opposed to being generalized to many targets of worry.

### **1.3.2.2 Posttraumatic Stress Disorder**

PTSD develops in response to a specific traumatic event that involved actual or threatened death/serious injury or a threat to physical integrity (APA, 2013). In the Diagnostic and Statistical Manual of Mental Disorders–Fifth Edition (DSM-5), PTSD is characterized by intrusions (e.g., distressing recollections, nightmares, and flashbacks of the event; psychological or physiological reactivity to cues that resemble the event), avoidance (e.g., efforts to avoid internal or external reminders of the event), negative alterations in cognitions and mood (e.g., distorted blame, persistent negative emotions, diminished interest in activities), and alterations in arousal and reactivity (e.g., hypervigilance, exaggerated startle response, sleep difficulty; APA, 2013).

In a review of PTSD and fear of recurrence, Smith, Redd, Peyser, and Vogl (1999) reported that many symptoms of PTSD have been documented among cancer survivors, including (DSM-IV-conceptualized) re-experiencing symptoms (intrusions; e.g., persistent, intrusive thoughts concerning cancer diagnosis or treatment, nightmares about the treatment experience) and avoidance/numbing symptoms (e.g., avoidance of thoughts or feelings associated with cancer diagnosis or recurrence, feelings of isolation/detachment/estrangement from others). In one study of Stage I to IV breast cancer survivors diagnosed 18-77 months earlier, Mehnert et al. (2009) found that 37% of the respondents experienced intrusive thoughts, 21% experienced avoidance, and 33% experienced hyperarousal. In this sample, a PTSD diagnosis,

based on a self-report measure designed to map onto DSM-IV-TR criteria, applied to 12% of the sample.

While breast cancer survivors with moderate to high levels of fear of recurrence report intrusive thoughts more frequently than survivors with low levels of fear of recurrence, some have argued that intrusive thoughts among cancer survivors are more related to *future-oriented* fears rather than thoughts about past experience (e.g., Simard, Savard, & Ivars, 2010). Whereas some cancer survivors may have PTSD with respect to their past cancer experience, it will be important to distinguish these cases from what we propose is a completely different construct, fear of recurrence. When comparing PTSD and fear of recurrence, some overlap was expected. However, we proposed that fear of recurrence would differ from PTSD in a critical aspect: in fear of recurrence, intrusive thoughts that occur are future-oriented rather than a “re-experiencing” of past events.

### **1.3.2.3 General Health Anxiety**

Potential clinical diagnoses associated with general health anxiety include illness anxiety disorder and somatic symptom disorder, which replaced hypochondriasis in a recent major revision to the somatic symptom disorders category of the DSM-5 (APA, 2013). In illness anxiety disorder, an individual has a preoccupation with having or acquiring illness, but somatic symptoms are not present or only mild in intensity, and if another medical condition is present or there is a high risk for developing a medical condition, the preoccupation is clearly excessive or disproportionate (APA, 2013). Other feature of this diagnosis include a high level of

anxiety about health, being easily alarmed about one's health status, and performance of excessive health-related behaviors (e.g., checking one's body for signs and symptoms of illness or maladaptive avoidance (e.g., of doctors; APA, 2013). By contrast, somatic symptom disorder involves one or more somatic symptoms that are distressing or disrupt daily life and excessive thoughts, feeling, or behaviors related to the somatic symptoms or health concerns (i.e, disproportionate and persistent thoughts about the seriousness of one's symptoms, persistently high anxiety about health or symptoms, or excessive time and energy devoted to these symptoms or concerns; APA, 2013).

To our knowledge, there has been no research investigating the link between fear of recurrence and these somatic symptom disorders; however, we expected to find a relation between these constructs. These diagnoses seems to bear some resemblance to Lee-Jones and colleagues' (1997) formulation of fear of recurrence in that these conditions could each involve excessive self-checking behavior, disruptive thoughts about one's symptoms, being easily alarmed by health triggers, and anxiety-related emotions.. Thus, we expected that fear of recurrence would be similar to a cancer-specific version of a somatic symptom disorder in which the individual experiences symptoms specifically focused on concerns about having cancer, but not other health issues.

### **1.3.3 Other Distinct Constructs**

Two constructs that we expected to be conceptually distinct from fear of recurrence were anhedonic depression and optimism.

### **1.3.3.1 Anhedonic Depression**

As mentioned earlier, the tripartite model of anxiety and depression aims to separate the common factor of negative affectivity from the specific factors of anxiety and depression (Clark & Watson, 1991). Thus, anhedonic depression refers to that aspect of depression that is relatively independent of anxiety, characterized by a lack of positive affect. Fear of recurrence has demonstrated moderate to strong, positive relations with depression symptoms, broadly, in past research (e.g., Koch et al., 2013; McGinty et al., 2012; Simard & Savard, 2009). While we expected fear of recurrence to be associated with depressive symptoms, we expected that there would not be as much overlap between fear of recurrence and depression as between fear of recurrence and anxiety constructs. Furthermore, using a more specific measure of anhedonic depression that is independent of anxiety, we expected somewhat smaller relations with fear of recurrence compared to the moderate-to-strong correlations that have been reported in the literature.

### **1.3.3.2 Optimism**

Dispositional optimism is a tendency to have positive outcome expectancies, such as expecting things to go one's way and generally believing that good things will happen (Scheier & Carver, 1985). Optimism has consistently demonstrated negative associations with fear of recurrence with correlations in the small-to-moderate range (e.g., Carver, Smith, Petronis, & Antoni, 2006; Deimling et al., 2006). While fear of recurrence is likely related to optimism, we expected these to be clearly distinct

constructs, as individuals may struggle with the uncertain possibility of a future recurrence without being pessimistic in general.

#### **1.4 Moderating Factors**

We also proposed that certain individual differences might attenuate the effects of fear of recurrence on negative behavioral outcomes including acceptance and avoidance. Previous research suggests that most cancer survivors are “concerned” about recurrence (Baker et al., 2005). Although many survivors may have distressing thoughts or emotions about the possibility of recurrence, not necessarily all of them will experience the aforementioned behavioral outcomes as consequences. We expected that individuals who are able to engage in more mindful acceptance of thoughts and emotions would be less affected (i.e., on behavioral outcomes) by them, even when their concerns and fears were relatively high.

Accumulating research suggests that mental health and behavior “are influenced more strongly by how people relate to their thoughts and feelings” than by the actual content and valence of them (Bond et al., 2011, p. 677). A construct known, variously, as acceptance, (inversely) psychological inflexibility, and (inversely) experiential avoidance, relates to a willingness to experience/tolerate unwanted emotions and thoughts, an ability to be in the present moment, and a commitment to “flexible, values-directed actions” in spite of negative psychological experiences (Bond et al., 2011, p. 679). Conversely, the opposite tendency includes “negative evaluations of feelings... avoidance of thoughts and feelings... [difficulty] distinguishing a thought from its referent... and [difficulty making] behavioral

adjustment in the presence of difficult thoughts or feelings (Bond et al., 2011, p. 677). To our knowledge, there has been no research investigating the link between fear of recurrence and psychological inflexibility or acceptance; however, we expected that individual differences in the ability to tolerate distress and move in a valued direction in spite of unpleasant psychological experiences would play a moderating role between fear of recurrence and behavioral outcomes (e.g., goal-striving, functional impairment, etc.).

Another variable that we expected to play a moderating role between fear of recurrence and behavioral outcomes was avoidance. Anxiety may lead some to engage in more reassurance-seeking behavior and others to engage in more avoidant behavior. We proposed that avoidance of potential triggers or thoughts and emotions related cancer recurrence would determine whether individuals engaged in more or less of the negative behavioral indicators of interest, including health care utilization and self-examination.

### **1.5 Overview of the Present Study and Hypotheses**

This study included 300 early-stage breast cancer survivors diagnosed within the past seven years. Participants completed a questionnaire that included multiple existing measures of fear of recurrence, additional theory-based items of fear of recurrence, measures of behavioral outcomes, as well as measures of other theoretically-related but distinct constructs (e.g., PTSD, uncertainty intolerance). Additionally, each participant's medical record was reviewed for supplemental clinical information.

### **1.5.1 Hypotheses related to Our Theory of Fear of Recurrence**

We proposed that fear of recurrence includes *cognitive* and *emotional* components. We hypothesized that cognitive components would include worry, specifically about future cancer, and risk perception elements, including a *discrepancy*, either between one's subjective perception of risk of recurrence and an objective estimate of risk, or between one's subjective perception of risk and one's perception of coping self-efficacy. We hypothesized that emotional components would include fear and anxiety. Therefore, we predicted that items assessing specific worries about recurrence (e.g., "I worry that a recurrence of cancer would threaten my life"), frequency/intensity of worry about recurrence (e.g., "How much time per day do you spend thinking about the possibility of cancer recurrence?"), and fear-related emotions (e.g., "When I think about the possibility of cancer recurrence, I feel worry, fear, or anxiety"), as well as items assessing threat appraisal/coping appraisal and/or threat appraisal/objective estimate of risk, would be part of a well-fitting model of fear of recurrence, and that the latent factor that these items load onto would be a significant predictor of relevant behavioral outcomes (e.g., health care utilization, self-examination, etc.).

### **1.5.2 Hypotheses related to Fear of Recurrence and Behavioral Outcomes**

As suggested above, we predicted that the fear of recurrence latent factor would be a significant predictor of each of the following behavioral outcomes: health care utilization, mental health treatment, physical self-examination, functional impairment, and goal-striving. We predicted that, in general, high levels of fear of

recurrence would be associated with greater functional impairment, greater likelihood of mental health treatment, and decreased goal-striving, although, as described below, we predicted that some of these relationships might also be moderated by acceptance or avoidance.

We predicted that fear of recurrence would have a curvilinear relationship with positive health changes, as low levels of fear of recurrence might be motivating to make helpful changes that may reduce the risk of recurrence, whereas high levels of fear of recurrence would be experienced as more incapacitating, interfering with life functioning and commitment to important values. We also explored whether the relationship between fear of recurrence and positive changes might be moderated by acceptance or avoidance.

#### **1.5.2.1 Moderating Role of Acceptance and Avoidance**

We predicted that acceptance would serve an important role in moderating the effects of fear of recurrence on behavioral outcomes. Namely, we predicted that greater acceptance would attenuate the negative effects of fear of recurrence, particularly on functional impairment and goal-striving. We predicted that, as fear of recurrence increases, functional impairment would increase and goal-striving would decrease; however, these effects would be attenuated when the survivor was high in acceptance.

We also posited that some survivors may exhibit a more avoidant response to fear of recurrence, whereas others may exhibit a more reassurance-seeking strategy. We hypothesized that fear of recurrence's relationships with health care utilization and

self-examination would be moderated by an avoidant response style. Namely, we predicted that, for those who are avoidant, the relationship between fear of recurrence and health system utilization would be negative or zero, whereas it might be positive for those low in avoidance. Likewise, for those who are avoidant, the relationship between fear of recurrence and self-examination would be negative or zero, whereas it would be positive for those low in avoidance. We also explored the possibility that acceptance or avoidance might moderate the relationship between fear of recurrence and positive health changes.

### **1.5.2.2 Predictive Power of Fear of Recurrence over Other Constructs**

We predicted that fear of recurrence would demonstrate greater predictive power of cancer-relevant behavioral outcomes when compared to other constructs. In particular, we predicted that fear of recurrence would be a better predictor of health care utilization, self-examination, and goal-striving when compared to the variables of anxious apprehension, uncertainty intolerance, and anxious arousal individually, and it would predict unique variance in these outcomes above and beyond these related constructs combined.

### **1.5.3 Hypotheses concerning Fear of Recurrence's relation to Other Similar Constructs**

We also assessed the extent to which fear of recurrence overlaps with, and is unique from, theoretically-similar constructs. Our overarching hypothesis was that fear of recurrence would demonstrate some overlap with other constructs but also would consistently emerge as a unique factor with distinguishing characteristics.

### **1.5.3.1 Theoretically-Similar and Dissimilar Constructs**

We predicted that fear of recurrence would be overlapping with anxious apprehension, uncertainty intolerance, and anxious arousal, but that factor analyses would demonstrate that these are distinct constructs. Furthermore, anxiety disorders vary with respect to the degree of anxious apprehension and anxious arousal involved. We predicted that fear of recurrence would be characterized by more anxious apprehension than anxious arousal and that fear of recurrence would therefore be more strongly correlated with anxious apprehension and uncertainty intolerance (i.e., moderate-sized, positive associations) than anxious arousal (i.e., small-sized, positive association).

We predicted that fear of recurrence would be less related to anhedonic depression and optimism. Therefore, we again predicted that factor analyses would demonstrate that these are clearly distinct constructs. We also predicted that, fear of recurrence would be weakly correlated with these constructs.

### **1.5.3.2 Multifaceted Clinical Constructs**

We predicted that fear of recurrence would be overlapping with GAD, PTSD, and general health anxiety, but that factor analyses would demonstrate that fear of recurrence differs from these multifaceted clinical constructs in critical ways.

With respect to GAD, we predicted, overall, a positive, small- to moderately-sized association between fear of recurrence and the general factor of GAD. However, while we predicted that fear of recurrence would have a moderate, positive association with the specific facet of GAD that involves frequent, pervasive, difficult-to-control

worry, it would have a weak or zero association with the facet of GAD that involves worry about many different topics. Thus, we predicted that, while fear of recurrence and GAD would demonstrate some overlap, a distinguishing feature between these constructs would be the content and diffusion of the worry. Namely, we predicted that, unlike the case of GAD where an individual worries about many minor topics, worry in fear of recurrence would be concentrated uniquely on the possibility of cancer recurrence.

With respect to PTSD, we predicted, overall, a small- to moderate-sized, positive correlation between fear of recurrence and the general factor of PTSD. However, we predicted that fear of recurrence would not be associated equally with the four symptom clusters of PTSD (i.e., intrusion, avoidance, negative alterations in cognitions and mood, and alterations in arousal and reactivity). Past descriptions of fear of recurrence (e.g., Lee-Jones et al., 1997) have highlighted more symptoms of avoidance and heightened arousal than re-experiencing. Also, while some studies have demonstrated relations between fear of recurrence and intrusive thoughts (e.g., Mehnert et al., 2009), others have argued that these intrusions relate to future events rather than "re-experiencing" past events (Simard et al., 2010). Thus, we predicted that, while fear of recurrence and PTSD, overall, would share some overlap, a distinguishing feature between these constructs would be re-experiencing/intrusion symptoms. We predicted that, unlike in PTSD, intrusive thoughts related to fear of recurrence would be *future-oriented* as opposed to retrospective in content. Therefore, we predicted that, when conducting factor analyses, fear of recurrence would be more

related (i.e., small- to moderate-sized positive relationships) to the unique facets of negative alterations in cognitions and affect, alterations in arousal and activity, and avoidance compared to the unique facet of intrusion (i.e., zero association).

Finally, we predicted that fear of recurrence would be similar to a cancer-specific version of general health anxiety—namely, fear of recurrence would not be strongly associated with somatic symptom disorder symptoms in general (e.g., worry about illness in general, concern about pain in general), but characterized by worry specific to cancer (e.g., worry about having cancer, concern that a pain is indicative of cancer). Therefore, we predicted that fear of recurrence would be associated with somatic symptom disorder symptoms framed around cancer (i.e., moderate-sized, positive relationships) but not such symptoms framed around illnesses other than cancer.

## **Chapter 2**

### **METHOD**

#### **2.1 Participants**

Three hundred early-stage breast cancer survivors diagnosed within the past seven years took part in this study. We recruited participants from Christiana Care Health System's (CCHS) Helen F. Graham Cancer Center & Research Institute (HFGCCRI) in Newark, DE. The inclusion criteria for this study were as follows: eligible survivors (1) received a primary diagnosis of Stage 0 (Ductal Carcinoma in situ or Lobular Carcinoma in situ), I, II, or IIIA breast cancer within the last seven years; (2) had completed any planned surgery, chemotherapy, or radiation treatment; (3) were at least 18-years-old; (4) were comfortable speaking, reading, and answering survey questions in English; and (5) could provide meaningful informed consent. The only exclusion criterion was having more than one diagnosis of cancer (i.e., a recurrence of breast cancer or any other cancer diagnosis, with the exception of basal or squamous cell skin cancer which were allowed).

We obtained a list of the 2971 patients with positive breast biopsies within the past seven years at the HFGCCRI. Of these, we screened and contacted a random sample of 1260 for participation. Before contacting these cancer survivors, we reviewed records to assess whether any may have subsequently died. We found that 42 of these individuals were deceased at the time of recruitment. We determined that an additional 55 survivors were ineligible, most because of a second cancer diagnosis.

We could not obtain current contact information for 65 of the survivors. Of the remaining survivors, 166 declined to participate and 398 were considered passive refusals (i.e., they did not respond to the letter or phone outreach attempts). For four survivors, research assistants initiated contact but did not complete the full recruitment outreach procedure (e.g., due to oversight). The number of survivors who verbally consented to participate was 507 (46.2% of potentially eligible participants).

Of the 507 who verbally agreed to participate, 386 (76.1%) returned consent forms. Of these, 369 (95.6% of those who returned consents; 72.8% of those who initially agreed; 35.2% of those who were potentially eligible) also submitted surveys. Of those who verbally agreed but did not submit surveys, 34 reported that they had changed their mind about participating, whereas the rest were passively lost to follow-up. Every effort was made to retain survivors who expressed interest in participating but who did not follow-through on submitting materials. We discarded surveys in excess of our recruitment goal including five from male breast cancer survivors (too few to make comparisons based on gender), two that indicated that the respondent was in fact ineligible for the study (i.e., they had had a second cancer diagnosis), eight that exhibited inattentive responding on an attention-check item, and eleven that were grossly incomplete (i.e., missing several items central to the study or non-adherent to instructions).

The demographic characteristics of the sample are presented in Figures 2.1 to 2.9. The racial/ethnic make-up of the final sample was 84.7% White, 12.7% Black, 2% Hispanic, 0.3% Asian, 0.3% American Indian or Alaskan Native, and 1% Other

(participants could select multiple options). The educational attainment of the sample was fairly evenly split into four categories: high school education, some college, a college degree, and some graduate education/a graduate degree. About half the sample (49.7%) was not working; 12.3% were working part-time, and 37.7% were working full-time. There was variability in household income; modal income was >\$100,000 (25.7% of the sample), and median income was \$60,000-80,000. About 68% of the sample was married, and 83.7% had children. Mean/median age was 62 years ( $SD = 11.4$ ; Range: 33-90 years). The sample was diverse across the spectrum of years since diagnosis (0-7 years). Most participants in the sample were Stage IA (46.7%), followed by Stage 0 (19.7%), and IIA (19%). There were no differences between removed and analyzed participants with regard to age, race, education, occupational status, income, relationship status, or stage at diagnosis.

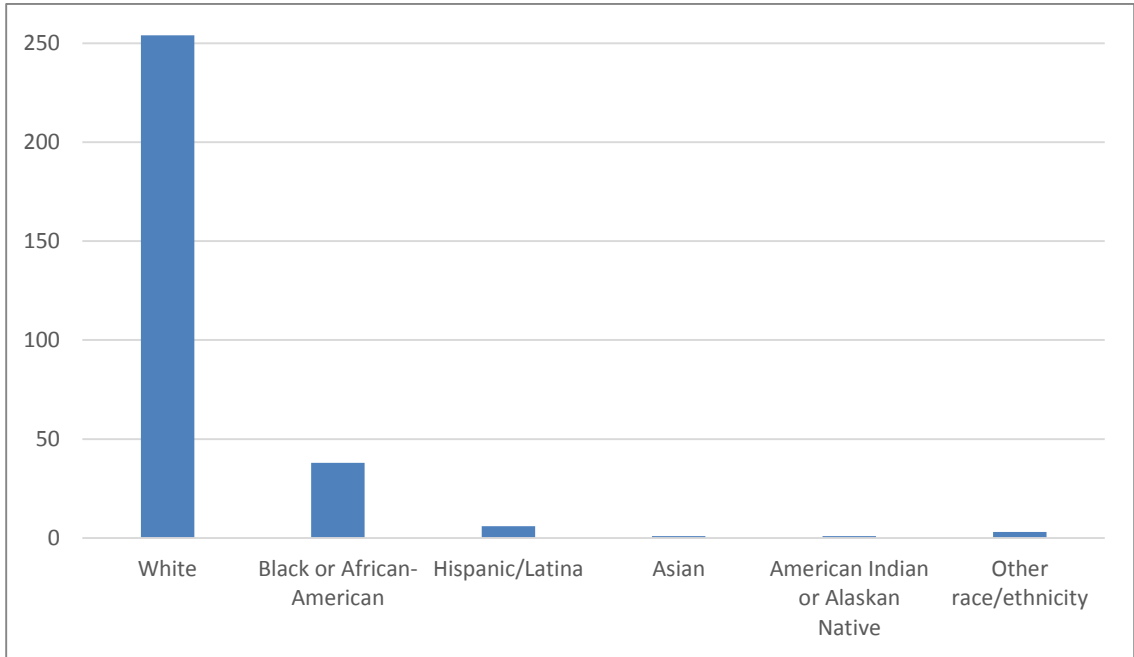


Figure 2.1 Frequency of race/ethnicity categories of the sample.

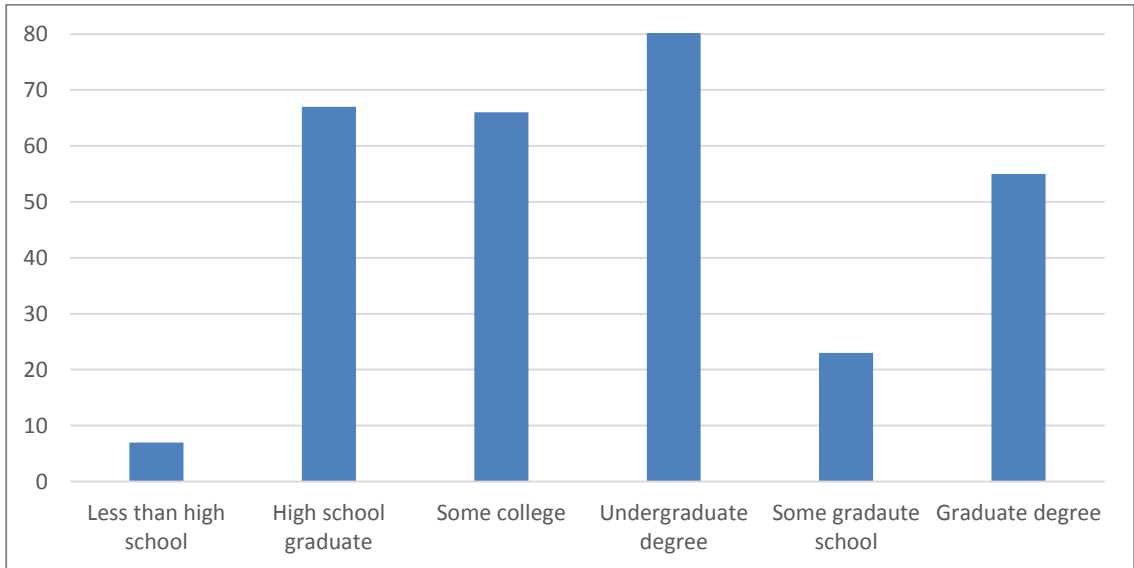


Figure 2.2 Frequency of educational attainment categories of the sample.

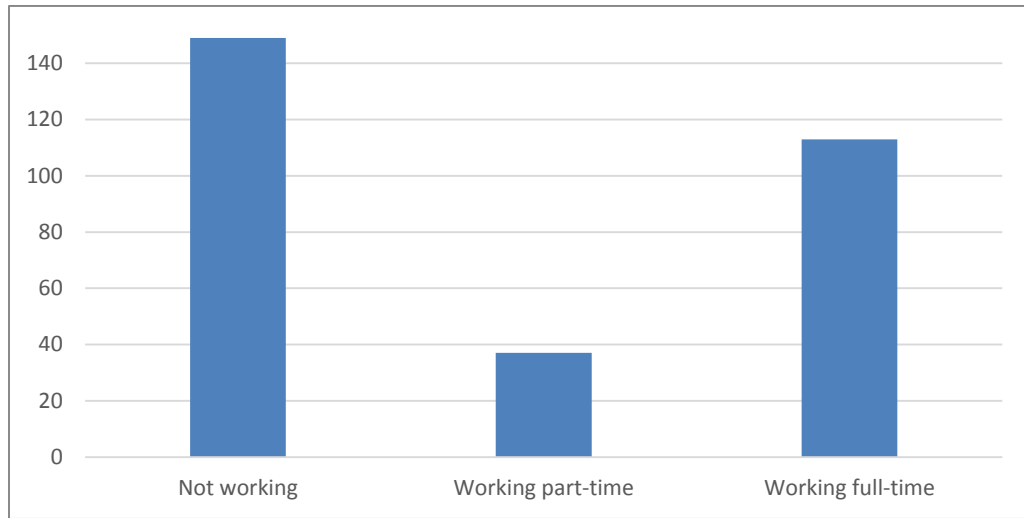


Figure 2.3 Frequency of work status categories of the sample.

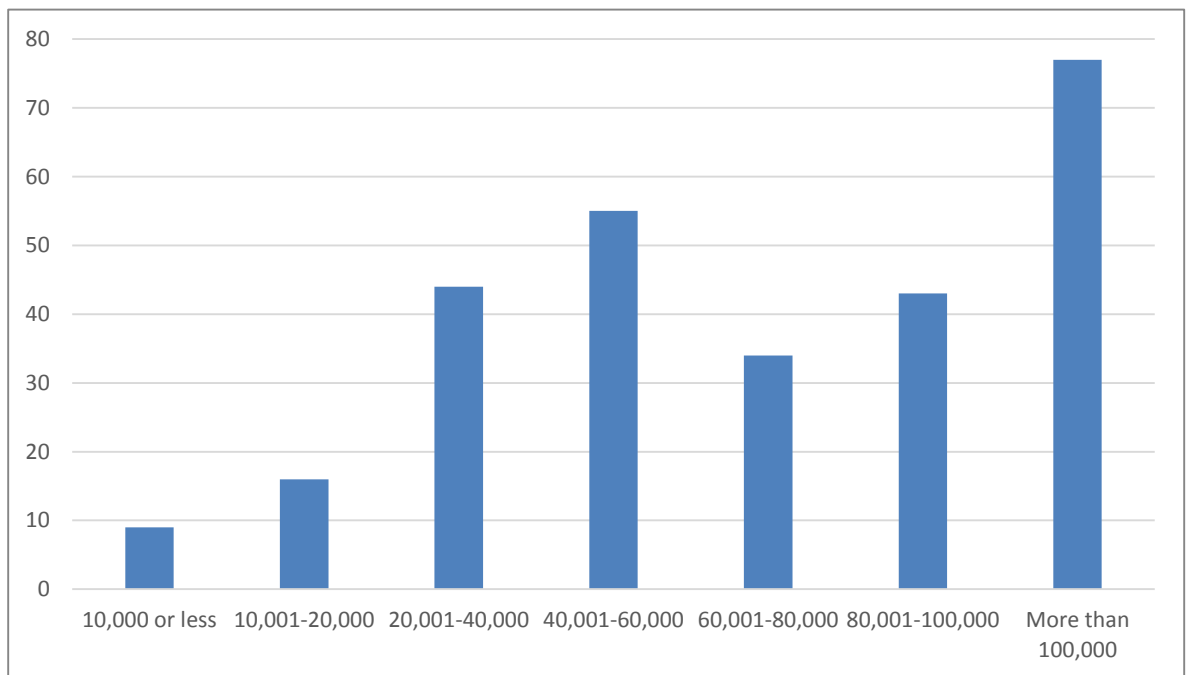


Figure 2.4 Frequency of household income categories of the sample.

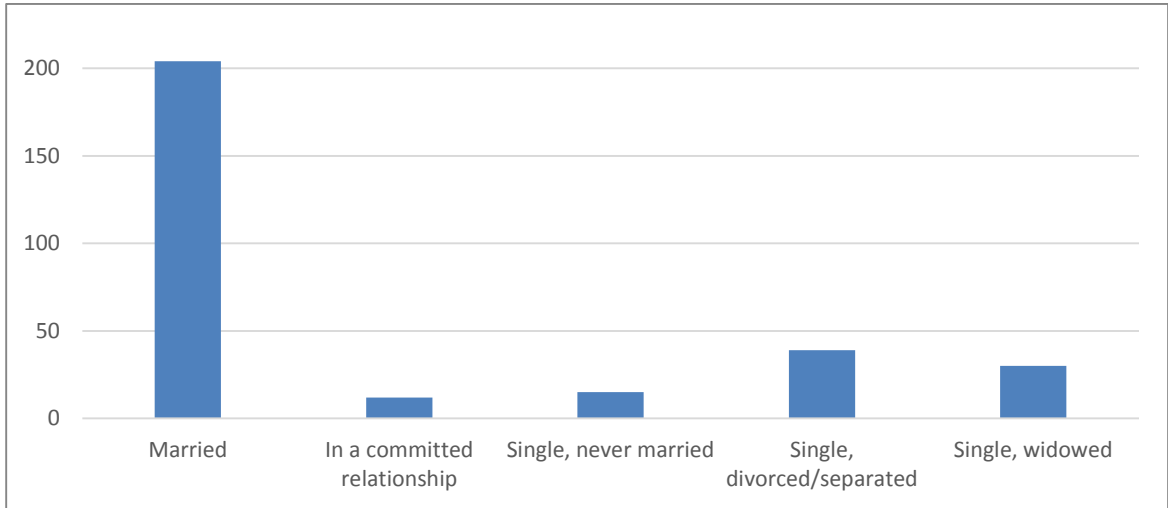


Figure 2.5 Frequency of relationship status categories of the sample.

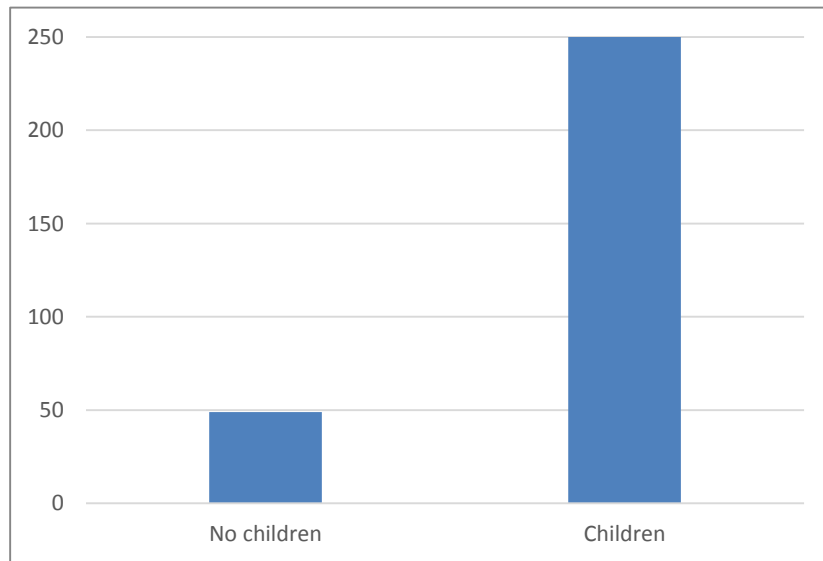


Figure 2.6 Frequency of parental status categories of the sample.

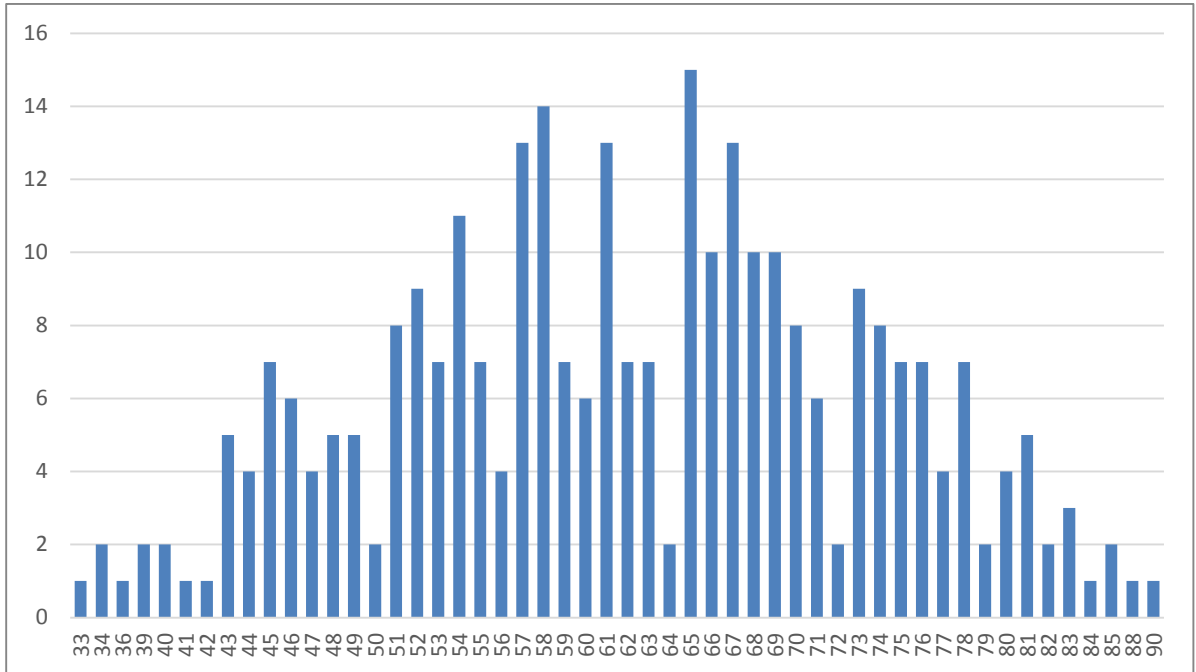


Figure 2.7 Frequency of age values of the sample.

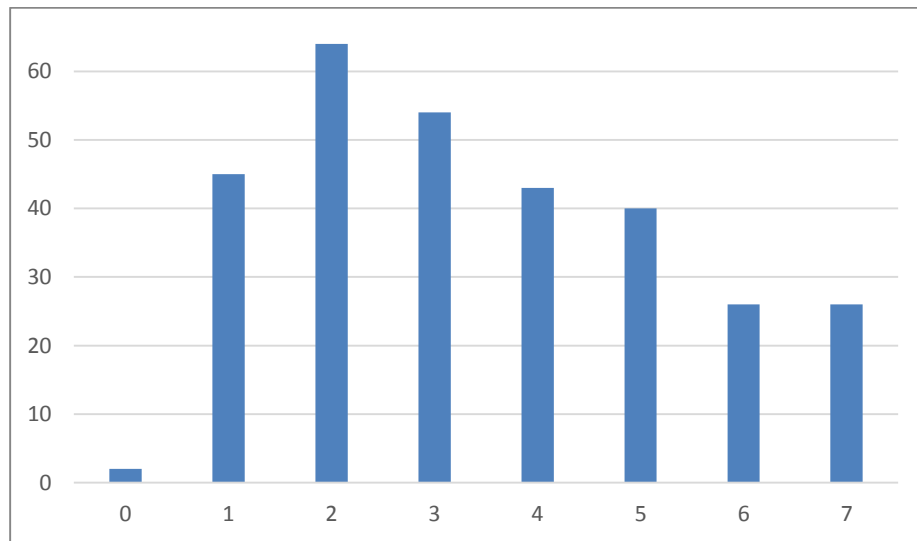


Figure 2.8 Frequency of years since diagnosis values of the sample.

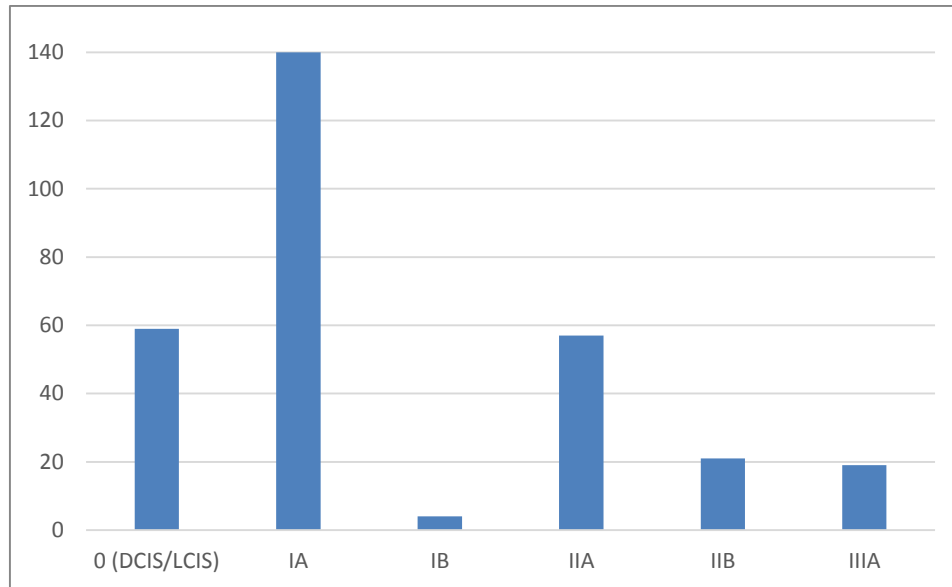


Figure 2.9 Frequency of stage categories of the sample.

## 2.2 Procedure

This project was approved by the CCHS Institutional Review Board. Recruitment involved first sending breast cancer survivors a letter with information about the study. We then followed up with a phone call to provide additional information, verify eligibility, and determine interest in participation. Breast cancer survivors expressing interest were mailed a consent form and reimbursement form. Upon return receipt of the signed forms, we e-mailed participants a link to the online questionnaire, administered through Qualtrics. Some participants requested to complete the questionnaire via paper and pencil, and we accommodated this request so as not to exclude participants who did not have access to or feel comfortable completing the online version of the questionnaire.

Among surveys completed online, the mean length of time that surveys were open was 178 minutes; however, we expect that many participants completed the survey over multiple intervals (the survey could remain open for up to seven days, and participants were able to close and later resume the survey from the point where they left off). The median length of time online surveys were open was 57 minutes. For their one-time involvement in this study, participants received \$20.

## **2.3 Measures**

### **2.3.1 Demographics and Clinical Characteristics**

Participants provided demographic information about their age, race, ethnicity, relationship status, children, education, work status, and income. We collected information about clinical characteristics such as time since diagnosis, cancer stage, and treatments received through self-report as well as chart review.

### **2.3.2 Fear of Recurrence**

Participants completed two fear of recurrence measures: the Fear of Cancer Recurrence Inventory (FCRI; Simard & Savard, 2009) and the Concerns About Recurrence Scale (CARS; Vickberg, 2003). The CARS is a breast cancer-specific measure, whereas the FCRI was developed for use across cancer disease sites. We selected these measures based on the results of a recent comprehensive review of fear of recurrence measures and their fit with the proposed theory of fear of recurrence. In a comprehensive review, Thewes et al. (2012) evaluated the relative merits of various existing measures of fear of recurrence. They noted that the Medical Outcomes Trust has defined a set of attributes and criteria for self-report measures used in cancer

research (Scientific Advisory Committee of the Medical Outcomes Trust, 2002). Thewes et al. (2012) evaluated each of the existing measures and determined that, among the longer measures of fear of recurrence (i.e., 10 or more items), the breast cancer-specific CARS had one of the highest ratings. With regard to the FCRI, Thewes et al. reported that this measure demonstrated the best psychometric properties. Furthermore, they noted that the FCRI is the only measure that has explored criterion validity by comparing the FCRI to a type of gold-standard measure—a clinical interview. Both the CARS and the FCRI have been validated in US and non-US samples (Thewes et al., 2012).

#### **2.3.2.1 The Fear of Cancer Recurrence Inventory**

The FCRI (Simard & Savard, 2009) is a 43-item, multifaceted measure that has been used to assess fear of recurrence among various disease site cancer survivors. It includes items related to triggers (e.g., "The following situations make me think about the possibility of cancer recurrence: an appointment with my doctor or other health professional; seeing or hearing about someone who is ill"), severity (e.g., "How much time per day do you spend thinking about the possibility of cancer recurrence?"), psychological distress (e.g., "When I think about the possibility of cancer recurrence, I feel: worry, fear or anxiety; helplessness or resignation"), functioning impairment (e.g., "My thoughts or fears about the possibility of cancer recurrence disrupt: my ability to make future plans or set life goals; my work or everyday activities"), insight (e.g., "I feel that I worry excessively about the possibility of cancer recurrence"), and coping strategies (e.g., "When I think about the possibility of cancer recurrence, I use

the following strategies to reassure myself: I try to find a solution; I tell myself to 'stop it'), and reassurance (e.g., " When I think about the possibility of cancer recurrence, I use the following strategies to reassure myself: I call my doctor or other health professional").

The authors of the FCRI developed the measure to assess a multidimensional conceptualization of fear of recurrence. They used an inclusive definition of fear of recurrence: "the fear or worry of the possibility that the cancer will return or progress in the same organ or in another part of the body," which reflects how survivors typically conceive of recurrence (Simard & Savard, 2009, p. 243). The authors also developed items in accordance with the cognitive-behavioral conceptualization of fear of recurrence inspired by the Lee-Jones et al. (1997) model described earlier and DSM-IV-TR anxiety and somatoform disorders.

The authors assessed the psychometric properties of an initial French-Canadian version of the FCRI in a large sample of cancer survivors who were heterogeneous with respect to cancer site, stage, and time elapsed since diagnosis (treatment within the past 10 years). The FCRI demonstrated strong internal reliability ( $\alpha = .95$ ; Simard & Savard, 2009). Evidence for convergent validity came from sizeable correlations with other measures of fear of recurrence (e.g., with the CARS overall fear subscale,  $r = .77$ ; Simard & Savard, 2009). The FCRI was also associated with increased intrusive thoughts ( $r = .66$ ), avoidance ( $r = .52$ ), anxiety symptoms ( $r = .64$ ), and depression symptoms ( $r = .43$ ), indicating that higher scores on the FCRI are associated with psychological distress (Simard & Savard, 2009). The FCRI also

demonstrated discriminant validity with small to moderate correlations with constructs not believed to be directly associated with fear of recurrence including physical, cognitive, and social functioning and global quality of life (Simard & Savard, 2009).

To complete the FCRI, participants rated each item on a scale from 0 to 4. Specific response anchors varied depending on the subscale (e.g., *Not at all* to *A great deal*; *Never* to *All the time*). In the present study, Cronbach's alpha for the FCRI was .94 for the Total score, .91 for the Triggers subscale, .89 for the Severity subscale, .89 for the Psychological Distress subscale, .93 for the Functioning Impairment subscale, .84 for the Insight subscale, .82 for the Coping Strategies subscale, and .62 for the Reassurance subscale. With regard to the Reassurance subscale, the scale includes two medical reassurance-seeking items and one self-examination item. Reliability testing revealed that, without the self-examination item, reliability would be improved to  $\alpha = .77$ .

### **2.3.2.2 The Concerns About Recurrence Scale**

The CARS (Vickberg, 2003) is a 30-item, breast cancer-specific, fear of recurrence questionnaire developed to understand the nature of fear of recurrence—what are breast cancer survivors worried about related to a recurrence? Also utilizing an inclusive definition, recurrence is defined in the CARS as follows: “By recurrence we mean the breast cancer coming back in the same breast or another area of the body, or a new breast cancer in either breast.” This formulation is consistent with the FCRI definition of fear of recurrence. The CARS includes two sections. The first covers overall fear of recurrence with four questions related to frequency, distress, duration,

and severity (e.g., "How much does the possibility that your breast cancer could recur upset you?"). Thus, the scale produces an overall fear index that addresses frequency, potential for upset, consistency, and intensity of fear of recurrence (Vickberg, 2003). The second section assesses the nature of survivors' concerns about breast cancer recurrence (i.e., "I worry that a recurrence of breast cancer would...") in four domains including health worries (e.g., "...threaten my physical health"), womanhood worries (e.g., "...make me feel I am less of a woman"), role worries (e.g., "...keep me from fulfilling important roles"), and death worries (e.g., "...threaten my life"). Thus, the CARS has a four-factor structure, relating to health worries (i.e., concern about future treatment, emotional upset, physical health, carrying out planned activities, and loss of breasts), womanhood worries (i.e., femininity, sexuality, womanhood, body image, romantic relationships, identity, and spirituality or faith), role worries (i.e., roles and responsibilities at work and at home, relationships with friends and family, physical ability to complete daily activities, financial problems, and self-confidence), and death worries (the possibility that a recurrence of breast cancer could lead to death; Vickberg, 2003).

In a sample of breast cancer survivors one to seven years post-diagnosis with no history of recurrence, the CARS demonstrated good internal reliability ( $\alpha = .87$  overall index;  $\alpha = .89-.94$  for subscales; Vickberg, 2003). The overall index correlated with intrusive thoughts ( $r = .64$ ), avoidance ( $r = .50$ ), distress (depression, anxiety, and loss of emotional and behavioral control;  $r = .54$ ), and well-being (general positive affect and emotional ties;  $r = -.44$ ; Vickberg, 2003). Each of the subscales also

correlated significantly with these external measures. Findings so far suggest that breast cancer survivors' fears tend to most commonly revolve death, further treatment, emotional difficulties, and physical limitations (Vickberg, 2003).

In completing the CARS, participants were asked to rate each worry item on a scale from 1 *Not at all* to 6 *Extremely*. Response anchors for the overall fear index items varied by item, but ranged from 1 to 6 (e.g., *Not at all afraid* to *Very afraid*; *I don't think about it at all* to *I think about it all the time*). In the present study, Cronbach's alpha was .89 for the overall fear index, .89 for the role worries subscale, .89 for the womanhood worries subscale, .95 for the health worries subscale, and .92 for the death worries subscale.

### **2.3.2.3 Additional Items to Assess Fear of Recurrence**

In addition to these two existing scales, we also included other items to assess aspects of fear of recurrence proposed in our model but not covered by the FCRI, CARS, or, to our knowledge, other existing measures of the construct. Namely, we included items related to the perceived discrepancy cognitive component of fear of recurrence discussed earlier.

#### **2.3.2.3.1 Perceived Risk**

To obtain participants' perceptions of risk, we asked, "What do you think your chance is of having breast cancer again (including a recurrence of the same breast cancer OR a new breast cancer) within the next [X] years?" where the X was 10 minus the number of years since diagnosis. Participants could fill in any number from 0 to 100%. Our goal was to obtain each participant's estimate of their chance of breast

cancer recurrence, broadly conceived, ten years from their diagnosis. In that regard, risk estimates were comparable across participants, in spite of differing lengths of time since diagnosis. Furthermore, having participants' 10-year risk perception estimates allowed us to directly compare each participant's perception of risk to a 10-year, objective estimate of risk that we calculated using clinical information from participants' medical records.

#### **2.3.2.3.2 Objective Risk Estimate**

In order to identify an effective strategy for calculating objective recurrence risk estimates, we consulted a Masters-level, Advanced Oncology Certified Nurse/Certified Breast Care Nurse, as well as the Chief of Medical Oncology at the HFGCCRI, who recommended a program called Adjuvant! Online ([www.adjuvantonline.com](http://www.adjuvantonline.com)), an online tool used by oncology professionals to calculate the benefit of adding various hormonal and chemotherapy treatments to patients' regimens. We utilized Adjuvant! Online retrospectively, calculating recurrence estimates based on the treatments survivors already received. We entered clinical information, most of which we obtained from participants' medical records, including age, extent of medical co-morbidity, ER status, tumor size, tumor grade, number of positive nodes, hormonal treatment received, and chemotherapy regimen received. This tool produces a 10-year risk estimate for mortality and recurrence (broadly conceived of as a recurrence of the same breast cancer or a new breast cancer, consistent with what we asked survivors).

Both participant perception of recurrence risk and the objective estimate of recurrence risk produced by Adjuvant! Online were on a scale of 0 to 100. We calculated a discrepancy score for each participant by subtracting the objective estimate of risk from the perceived risk; therefore, positive scores represent an overestimation of risk, zero represents an accurate estimation of risk, and negative scores represent an underestimation of risk.

### **2.3.2.3.3 Perceived Coping Efficacy**

Influenced by McGinty et al.'s (2012) threat-coping appraisal model, we asked participants “If you were to experience a recurrence of cancer, how would you rate your ability to cope with it?” Response options ranged from 1 (*I would not be able to cope with it*) to 5 (*I am confident I could cope*).

To compute the discrepancy between perceived risk (values of 0-100) and coping efficacy (values of 1 to 5), we first put these variables on the same scale by calculating z-scores for each participant. We then subtracted participants’ perceived coping efficacy z-score from their perceived risk of recurrence z-score. Thus, higher values represent a threatening discrepancy between risk and coping appraisal (high risk appraisal, low coping appraisal), whereas low (negative) values represent a favorable discrepancy between risk and coping appraisal (low risk appraisal, high coping appraisal). Finally scores close to zero represent a balance of risk and coping appraisal (e.g., a high risk appraisal but a balancing high coping appraisal; low coping appraisal but also a low risk appraisal).

### **2.3.3 Behavioral Outcomes**

We measured a variety of self-reported behavioral outcomes that we expected to be related to fear of recurrence.

#### **2.3.3.1 Health Care Utilization**

To assess health care utilization, participants were asked whether they had made any phone calls or had any visits to their oncology medical providers' or primary care physician's offices within the past three months and how many phone calls and visits they had made to their providers' offices within the past year.

#### **2.3.3.2 Mental Health Treatment**

We asked participants whether they sought out mental health services including psychotherapy and medication since their cancer diagnosis. Items included: "At any point after your cancer treatment, did you seek out mental health services such as psychotherapy or counseling?" "Since your cancer treatment, have you taken or been prescribed any psychotropic medications—that is, medications that are intended to affect mood or behavior?" and "Since your cancer treatment, has anyone (e.g., relative, friend) suggested to you that you may benefit from mental health services?" Participants responded "yes" or "no" to whether each of these had occurred.

#### **2.3.3.3 Self-Examination**

To assess physical self-examination, we asked the following question: "How often do you check your body for signs or symptoms cancer?" Response options ranged from 1 to 8 corresponding to *Never*, *A few times a year*, *About once a month*,

*About once a week, A few times a week, Daily, A few times a day, and Several times a day.*

#### **2.3.3.4 Functional Impairment**

We used the composite score from the Functioning Impairment subscale of the aforementioned FCRI (Simard & Savard, 2009) to assess this outcome. Each question takes the form: “My thoughts or fears about the possibility of cancer recurrence disrupt...” and items include “my social or leisure activities,” “my work or everyday activities,” “my relationships with my partner, my family, or those close to me,” etc. Response options ranged from 0 (*Not at all*) to 4 (*A great deal*). As noted above, Cronbach’s alpha for this subscale was .93.

#### **2.3.3.5 Goal-Striving**

To assess forward life action, we provided participants with a checklist of common events that indicate forward movement and goal-striving in life. Participants indicated “yes” or “no” to whether they engaged in any of the activities during the past year. Items were adapted from a life events schedule that we have used in previous research (Sandler & Lakey, 1982), for example: “developed relationships with people who have new and interesting ideas or lifestyle,” “began a new job or volunteer position,” “pursued an educational goal/advanced my education,” and “joined a social organization.”

To complement this measure, we also included a measure of “prosperity,” the 8-item Flourishing Scale (Diener et al., 2009). Participants rated how much they agree with statements on a scale from 1 (*Strongly disagree*) to 7 (*Strongly agree*), for

example, “I lead a purposeful and meaningful life” and “I am engaged and interested in my daily activities.” The Flourishing Scale was designed to be a brief measure of social–psychological prosperity, including aspects of human functioning ranging from positive relationships, to feelings of competence, to having meaning and purpose in life (Diener et al., 2010). A high score would suggest that the respondent views herself in positive terms in important areas of functioning. The scale has been shown to produce one robust factor and has demonstrated internal reliability ( $\alpha = .87$ ), one-month test-retest reliability ( $r = .71$ ), and convergent validity via strong correlations with similar measures of psychological well-being in a sample of undergraduate students (Diener et al., 2010). In the present study, Cronbach’s alpha was .93.

Finally, as a balance, we also included an exploratory list of “disengagement” items that would indicate detachment from meaningful life activities or decreased goal-striving and forward action. As with the engagement items, participants indicated “yes” or “no” to whether they completed any of the activities during the past year with items such as “Cancelled future plans or purchases (e.g., vacation, home renovation, other major purchase),” “Left my job or volunteer position (other than planned retirement),” and “Pulled away from personal relationships (e.g., broke off relationship with a romantic partner or distanced self from a friend).”

#### **2.3.3.6 Positive Health Changes**

To assess positive life changes, we provided participants with a checklist of healthful behaviors, most of which are associated with a reduced risk of cancer recurrence, for example, “began to engage in more exercise,” “began to eat a healthier

diet,” “cut back on alcohol consumption,” “cut back on or quit smoking,” “worked on developing a stronger social support network,” and “engaged in more self-care with regard to mental health (e.g., reduced stressors in my life, engaged in more relaxation or mindfulness practice, etc.)” Participants indicated the extent to which they had made each change since their diagnosis with response options ranging from 1 (*I did not make a change*) to 5 (*Very much*). In the present study, Cronbach’s alpha was .88.

### **2.3.4 Related Constructs**

We included measures of related constructs including anxious apprehension, anxious arousal, uncertainty intolerance, anhedonic depression, optimism, GAD, PTSD, and general health anxiety. We also included a measure of acceptance, which we predicted would moderate the relationship between fear of recurrence and behavioral outcomes.

#### **2.3.4.1 Anxious Apprehension**

Participants completed the Penn State Worry Questionnaire (PSWQ; Meyer, Miller, Metzger, & Borkovec, 1990). This widely-used, 16-item scale assesses an individual's tendency to worry excessively. Participants rate, on a scale from 1 (*Not at all typical*) to 5 (*Very typical*) how characteristic each item is of them, for example, "Once I start worrying, I can't stop," "Many situations make me worry," and "My worries overwhelm me." The PSWQ has demonstrated high internal reliability ( $\alpha = .86-.93$  in clinical and college samples) and test-retest reliability ( $r_s = .74-.93$  across periods ranging from two to ten weeks; Molina & Borkovec, 1994). Evidence for convergent and discriminant validity comes from strong correlations with other worry

scales and moderate correlations with depression (Davey, 1993; Molina & Borkovec, 1994). In the present study, Cronbach's alpha was .94.

#### **2.3.4.2 Uncertainty Intolerance**

Participants completed the short-form of the Intolerance of Uncertainty Scale (IUS-12; Carleton, Norton, & Asmundson, 2007). The IUS-12 was developed as a shorter and more psychometrically stable version of the Intolerance of Uncertainty Scale (IUS; Freeston, Rheaume, Letarte, Dugas, & Ladouceur, 1994). The IUS-12 contains 12 items that are intended to assess an individual's intolerance of the notion that negative events may occur and there is no definitive way of predicting or avoiding them. Participants rate how much they agree with various statements, for example, "It frustrates me not having all the information I need" and "Unforeseen events upset me greatly." Among two samples of undergraduate students, the IUS-12 demonstrated high internal reliability ( $\alpha = .91$ ; Carleton et al., 2007). The scale also correlates strongly with the original 27-item measure ( $r = .96$ ; Carleton et al., 2007). The authors of the IUS-12 found support for a two-factor structure of the scale, and they labeled the two factors prospective anxiety (fear and anxiety about future events) and inhibitory anxiety (uncertainty inhibiting action or experience;  $\alpha = .85$  for each; correlation between factors,  $r = .73$ ; Carleton et al. 2007). The authors found evidence for the convergent validity of the measure in that it was significantly correlated with measures of anxiety (e.g., GADQ:  $r = .61$ ; PSWQ:  $r = .54$ ). The IUS was also associated with depression symptoms ( $r = .56$ ; Carleton et al., 2007). In the present study, Cronbach's alpha was .90.

#### **2.3.4.3 Anxious Arousal**

Participants completed the Anxious Arousal subscale of the Mood and Anxiety Symptoms Questionnaire (MASQ; Clark & Watson, 1991). The Anxious Arousal scale was designed to assess anxiety symptoms that are independent from depression symptoms—those anxiety symptoms not part of a general negative affectivity factor. Participants indicated to what extent they experienced a variety of symptoms "during the past week, including today" on a scale from 1 (*Not at all*) to 5 (*Extremely*), for example, "Had pain in my chest," "Startled easily," and "Was trembling or shaking." The MASQ has demonstrated good internal reliability in an adult sample ( $\alpha = .88$ ). It demonstrated convergent validity via strong correlations with other anxiety measures and discriminant validity with depression, given only moderate correlations (Watson et al., 1995). Cronbach's alpha was .86 for the Anxious Arousal subscale in the present study.

#### **2.3.4.4 Generalized Anxiety Disorder**

The aforementioned PSWQ was used to assess for the excessive worry component of GAD. To get at a distinguishing feature of GAD—worry about many minor issues—participants also completed items adapted from the Generalized Anxiety Disorder Questionnaire-IV (GADQ-IV; Newman et al., 2002). One item asks, "Do you worry excessively or uncontrollably about minor things such as being late for an appointment, minor repairs, work projects, etc.?" A second item asks participants to list topics about which they worry excessively or uncontrollably. Finally, participants indicated whether or not they have been experiencing any of the

associated symptoms of GAD during the past six months (e.g., difficulty concentrating, muscle tension). Cronbach's alpha for these items in the present study was .73.

#### **2.3.4.5 Posttraumatic Stress Disorder**

Participants completed the PTSD Scale—Self-Report for DSM-5 (PS-SR-5; unpublished measure with permission by Edna B. Foa). The PS-SR-5 is a 24-item measure of PTSD symptoms that map directly on to DSM-5 criteria for the disorder. Accordingly, the scale assesses the symptom clusters of intrusions, avoidance, negative alterations in cognition and mood, and hyperarousal. Participants were asked to complete the PS-SR-5 specifically with respect to their cancer experience and rate 20 symptom items based on how often the symptom has been happening and how much it upset them over the past month. Items were rated on a scale 0 (*Not at all*) to 4 (*6 or more times a week/severe*). Additionally, four items for diagnostic utility are included that assess for distress and interference (necessary for PTSD diagnosis regardless of endorsement of symptoms) as well as two items assessing onset and duration (also used for diagnostic purposes). In our factor analyses, we used only the 20 symptom items. Studies on the psychometric properties of the PS-SR-5 are still underway; however, the predecessor to the PS-SR-5, the PTSD Symptom Scale—Self-Report (PSS-SR) for DSM-IV has demonstrated good reliability (e.g., Foa, Riggs, Dancu, & Rothbau, 1993). In our study, Cronbach's alpha was .94 for the 20 symptom items.

#### 2.3.4.6 General Health Anxiety

Participants completed select items of the Illness Attitudes Scale (IAS; Stewart & Watt, 2000) that we modified to assess health anxiety symptoms specific to cancer as well as health anxiety symptoms related to illnesses other than cancer. The IAS is one of the most frequently used questionnaires for hypochondriasis (the precursor to our current somatic symptom disorders) and is considered the gold-standard in self-rated assessment of this condition (Weck, Bleichhart, & Hiller, 2010). Several studies have demonstrated the reliability and validity of the IAS, including high 1-month test-retest reliability (e.g., subscales  $r_s = 0.62-1.0$  among adults), internal consistency (e.g., subscales  $\alpha_s = .62-.93$ , except the disease phobia scale,  $\alpha = .23$ , among undergraduates; e.g., Weck et al., 2010). Further, individuals with what would have previously been diagnosed as hypochondriasis have been found to score significantly higher than other psychiatric patients on most of the subscales, and the IAS is significantly correlated with other questionnaires that assess hypochondriacal attributes (e.g., Weck et al., 2010).

In the present study, participants completed nine items taken from the subscales that are considered most relevant to the diagnosis of hypochondriasis and that could be framed as specifically related to concerns about illnesses other than cancer. These included worry about illness (e.g., "Do you worry about your health *in general?*"), concern about pain (e.g., "If you have pain, do you worry that it may be caused by a serious illness *other than cancer?*"), hypochondriacal beliefs (e.g., "Do you believe that you have a physical disease *other than cancer*, but the doctors have

not diagnosed it correctly?"), and disease phobia (e.g., "Are you afraid that you may have another serious illness *other than cancer?*"; italics represent changes from the original question). We also included four of these same items framed to be about cancer, including concerns about pain (e.g., "If you have pain, do you worry that it may be caused by *cancer?*") and hypochondriacal beliefs (e.g., "Do you believe that you have *cancer*, but the doctors have not diagnosed it correctly?"). Cronbach's alpha in the current study was .76 for the cancer-specific items, .87 for the non-cancer-specific items, and .88 for the combined items.

#### **2.3.4.7 Anhedonic Depression**

Participants completed the Anhedonic Depression subscale of the aforementioned MASQ short-form (Clark & Watson, 1991). The Anhedonic Depression scale was designed to assess depressive symptoms that are independent from anxiety symptoms—those depression symptoms not part of a general negative affectivity factor. Participants indicated to what extent they experienced a variety of symptoms "during the past week, including today" on a scale from 1 (*Not at all*) to 5 (*Extremely*), for example, "Felt like nothing was very enjoyable" and "Felt like it took extra effort to get started." The Anhedonic Depression scale has shown internal reliability and convergent validity via strong correlations with other depression measures (e.g., Watson et al., 1995). Cronbach's alpha in the present study was .90 for the Anhedonic Depression subscale.

#### **2.3.4.8 Optimism**

Participants completed the Life Orientation Test-Revised (LOT-R; Scheier, Carver, & Bridges, 1994). The LOT-R consists of six items including statements such as “I’m always optimistic about my future” and “Overall, I expect more good things to happen to me than bad.” Participants indicated how much they agree with each statement on a 5-point scale ranging from 1 (*I disagree a lot*) to 5 (*I agree a lot*). The LOT-R has been widely used and has consistently shown good internal consistency, test-retest reliability, and convergent and discriminant validity (e.g., Scheier et al., 1994). In the present study, Cronbach’s alpha was .86.

#### **2.3.4.9 Acceptance**

Participants completed the Acceptance and Action Questionnaire-II (AAQ-II; Bond et al., 2011), which was designed to measure acceptance (or, psychological inflexibility/experiential avoidance). Participants rated 10 items on a scale ranging from 1 (*Never true*) to 7 (*Always true*) that reflect an unwillingness to experience unwanted emotions and thoughts (e.g., “I’m afraid of my feelings”), the ability to be in the present moment (e.g., “I am in control of my life”), and commitment to flexible values-directed actions when experiencing psychological events that could undermine them (e.g., “My thoughts and feelings do not get in the way of how I want to live my life”). The AAQ-II has demonstrated good internal reliability, test-retest reliability, and discriminant validity, and it concurrently, longitudinally, and incrementally predicts a range of outcomes predicted by theory (Bond et al., 2011). In the present study, Cronbach’s alpha was .85.

#### **2.3.4.10 Avoidance**

One item from the aforementioned FCRI was used to assess avoidance of cancer-related reminders: “Generally, I avoid situations or things that make me think about the possibility of cancer recurrence.” As with the FCRI items described above, this item was rated on a scale ranging from 0 (*Never*) to 4 (*All the time*).

## Chapter 3

### RESULTS

#### 3.1 Description of the Sample

Descriptive statistics for the major study variables are listed in Table 3.1. The bivariate correlations between the major study variables are listed in Table 3.2.

Table 3.1 Descriptive Statistics of Major Study Variables

Variable <sup>a</sup>	Min	Max	Mean	SD
How often do you think about the possibility of cancer recurrence?	1.00	5.00	2.08	0.83
I am worried or anxious about the possibility of cancer recurrence.	1.00	5.00	2.63	1.23
I worry that a recurrence of cancer would cause me to die.	1.00	5.00	3.00	1.55
Perceived-objective risk discrepancy (difference score)	-56.00	84.20	8.61	27.25
Perceived risk of recurrence	0.00	100.00	27.64	26.09
Objective estimate of recurrence risk	3.40	60.40	17.95	10.06
Anxious apprehension	1.00	5.00	2.83	0.88
Uncertainty intolerance	1.00	4.83	2.18	0.74
Anxious arousal	1.00	4.00	1.44	0.47
Optimism	1.00	5.00	3.81	0.95
Positive changes	1.00	4.50	2.40	0.89
Anhedonic depression	1.00	4.71	1.77	0.85
PTSD symptoms	0.00	3.15	0.39	0.57
Cancer-related health anxiety	1.00	5.00	1.62	0.69
Non-cancer-related health anxiety	1.00	5.00	2.04	0.70
Acceptance	1.80	7.00	5.52	0.97
Avoidance	1.00	5.00	2.26	1.15
Flourishing	1.00	7.00	6.11	0.94
Engagement (sum)	0.00	12.00	3.80	2.15
Disengagement (sum)	0.00	5.00	0.58	0.89
Self-examination	1.00	7.00	3.15	1.30
Functional impairment	1.00	5.00	1.49	0.79
Annual oncology visits	0.00	75.00	3.46	7.79
Annual oncology calls	0.00	14.00	0.79	1.53
Annual primary care visits	0.00	10.00	2.46	1.95
Annual primary care calls	0.00	13.00	1.48	2.11

<sup>a</sup>Each scale/item is based on a mean score unless otherwise noted.

Table 3.2 Bivariate Correlations between Major Study Variables

Variables: 1. "How often do you think about the possibility of cancer recurrence?" 2. "I am worried or anxious about the possibility of cancer recurrence." 3. "I worry that a recurrence of cancer would cause me to die." 4. Perceived-objective risk discrepancy, 5. Perceived risk of recurrence, 6. Objective estimate of recurrence risk, 7. Anxious apprehension, 8. Uncertainty intolerance, 9. Anxious arousal, 10. Optimism, 11. Positive health changes, 12. Anhedonic depression, 13. PTSD symptoms, 14. Cancer-related health anxiety, 15. Non-cancer-related health anxiety, 16. Acceptance, 17. Avoidance, 18. Flourishing, 19. Engagement, 20. Disengagement, 21. Self-examination, 22. Functional impairment, 23. Annual oncology visits, 24. Annual oncology calls, 25. Annual primary care visits, 26. Annual primary care calls.  
 \*  $p < .05$ . \*\*  $p < .01$

	1	2	3	4	5	6	7	8	9	10	11	12
2	.63**											
3	.61**	.46**										
4	.42**	.47**	.29**									
5	.45**	.53**	.34**	.93**								
6	.06	.07	.07	-.36**	.01							
7	.48**	.37**	.39**	.27**	.26**	.02						
8	.41**	.30**	.31**	.27**	.28**	-.01	.64**					
9	.36**	.29**	.21**	.21**	.24**	.03	.42**	.37**				
10	-.40**	-.37**	-.34**	-.31**	-.36**	-.09	-.60**	-.52**	-.38**			
11	.02	-.07	.13*	-.03	-.04	.03	-.04	.00	.09	.05		
12	.42**	.38**	.25**	.29**	.32**	.05	.50**	.52**	.71**	-.50**	.02	
13	.48	.50**	.35**	.18**	.22**	.12*	.40**	.49**	.62**	-.43**	.06	.73**
14	.63**	.57**	.46**	.37**	.40**	.09	.42**	.40**	.31**	-.34**	.05	.34**
15	.53**	.34**	.49**	.36**	.36**	-.01	.41**	.43**	.43**	-.46**	.14*	.42**
16	-.38**	-.33**	-.30**	-.21**	-.25**	-.10	-.54**	-.60**	-.52**	.65**	.03	-.62**
17	.43**	.27**	.33**	.14*	.19**	.14*	.24**	.31**	.22**	-.25**	.10	.29**
18	-.23**	-.29**	-.17**	-.24**	-.29**	-.12*	-.33**	-.35**	-.40**	.56**	.14*	-.56**
19	.04	.05	.03	-.09	-.08	-.03	-.10	-.02	-.02	.15**	.24**	-.16**
20	.21**	.16**	.21**	.06	.16**	.15*	.20**	.31**	.41**	-.28**	.08	.39**
21	.19**	.18**	.21**	-.01	.04	.07	.11	.07	.07	-.09	.18**	.09
22	.45**	.41**	.34**	.23**	.30**	.17**	.35**	.44**	.44**	-.40**	.11	.51**
23	.09	.20**	.09	.12	.09	-.02	.08	.09	.14*	-.05	-.06	.17**
24	.19**	.23**	.23**	.16**	.11	-.09	.18**	.16**	.14*	-.12*	.07	.13*
25	.13*	.09	.06	.03	.08	.11	.11	.09	.38**	-.18**	.05	.26**
26	.18*	.09	.16**	.01	.03	.08	.11	.04	.36**	-.17**	.15*	.19**

Table 3. 2 Continued

	13	14	15	16	17	18	19	20	21	22	23	24	25
14	.48**												
15	.43**	.54**											
16	-.60**	-.40**	-.48**										
17	.41**	.40**	.36**	-.28**									
18	-.43**	-.18**	-.33**	.61**	-.15**								
19	-.02	.12*	.09	.09	.02	.21**							
20	.32**	.14*	.29**	-.40**	.22**	-.32**	.04						
21	.13*	.11	.02	-.03	.04	.06	.09	.04					
22	.64**	.45**	.42**	-.58**	.31**	-.35**	.01	.35**	.19**				
23	.29**	.09	.12*	-.11	.08	-.03	-.10	.04	-.02	.20**			
24	.26**	.16**	.15**	-.16**	.14*	-.08	-.07	.03	.07	.25**	.51**		
25	.22**	.11	.29**	-.25**	.13*	-.19**	.05	.28**	-.08	.21**	.07	.11	
26	.23**	.14*	.31**	-.20**	.18**	-.14*	.15**	.24**	.01	.18**	-.03	.20**	.61**

Putting our measures on the same scales as were used in previous research, we can compare the values found in the present study to those reported in the literature. We obtained a mean total score of 56.94 for the FCRI total scale, which is comparable to but slightly lower than the mean total score of 60.6 obtained from a breast cancer survivor sample treated within the past 10 years in a study by the measure's authors (Simard & Savard, 2009). We obtained a mean score of 2.58 on the CARS overall fear subscale, which is again slightly lower than the mean score of 2.91 obtained from a breast cancer sample diagnosed one to seven years earlier in a study by the measure's author (Vickberg, 2003). We obtained a mean total score of 45.28 on the PSWQ. In a sample of breast, gynecological, ovarian, or endometrial cancer survivors within two years of diagnosis, the mean total PSWQ score was 43.3 (Wu et al., 2013). We obtained a mean total score of 20.16 on the IUS-12. In a sample of various stage breast cancer survivors diagnosed within the past five years, the mean total score on the IUS-12 was somewhat higher than ours at 27.59 (Jones et al., 2014). To our

knowledge, average scores for the AAQ-II and MASQ have not been reported in the literature for breast cancer patient/survivor samples.

We took into account non-normality of our outcome variables when conducting our analyses. Namely, we had a number of count outcomes characterized by many zero values, such as disengagement and calls/visits to providers. Although engagement was also a count outcome, it was normally distributed, so we treated it as a continuous variable. Mental health outcomes and the occurrence of calls/visits to providers in the past three months were binary and treated as such. The theory-consistent items that we included in our fear of recurrence model were each relatively normally distributed, including the discrepancy items.

We employed a variety of structural equation modeling (SEM) strategies to analyze the data including traditional confirmatory factor analysis (CFA), exploratory structural equation modeling (ESEM) and bifactor modeling. We used Mplus 7 (Muthén & Muthén, 1998-2012), a statistical software program that is flexible in its ability to accommodate non-normal outcome variables, to complete these analyses.

### **3.2 Modeling Fear of Recurrence**

Our first task was to specify and evaluate a fear of recurrence model reflecting our proposed, cognitive-emotional theory. Based on our theoretical conceptualization, we proposed that fear of recurrence includes cognitive features, including future-oriented *worry* and a cognitive *discrepancy*, and emotional features including *fear and anxiety*. Therefore, we predicted that items assessing worry, a cognitive discrepancy,

and fear-related emotions would be part of a well-fitting model of fear of recurrence and predictive of relevant behavioral outcomes.

Consistent with that prediction, we drew theory-consistent items from the pool of items completed by participants including the following: “I am worried or anxious about the possibility of recurrence,” “I am afraid of cancer recurrence,” “When I think about the possibility of cancer recurrence, I feel worry, fear, or anxiety,” “I worry that a recurrence of cancer would threaten my life,” “I worry that a recurrence of cancer would cause me to die,” “How often do you think about the possibility of cancer recurrence?” as well as the two discrepancy items described earlier, one that represents a discrepancy between perceived risk of recurrence and an objective estimate of risk of recurrence, and one that represents a discrepancy between perceived risk of recurrence and perceived ability to cope with a recurrence if one were to occur. Although there are many existing measures of fear of recurrence, our aim was not to test a specific measure but to evaluate a theory of fear of recurrence using theory-consistent items. Both the FCRI and the CARS contain theory-consistent items, but they are also broader in scope than the specific fear of recurrence theory proposed here (e.g., the FCRI includes insight, coping, reassurance scales). Thus, we selected the most theory-consistent items from these existing measures to test a narrower conceptualization of fear of recurrence.

We evaluated model fit of the theory-consistent items. Although there are no universally agreed upon cut-offs for fit statistics, a few guidelines are provided. Generally speaking, the smaller the value of the  $\chi^2$  statistic, the better the model fit,

and a non-significant value of  $\chi^2$  is an indication of good fit; however,  $\chi^2$  is influenced by sample size, and models with more than 200 cases are almost always significant. Another method for evaluating  $\chi^2$  is to divide it by the degrees of freedom. A resulting value less than or equal to three would indicate reasonably good fit (Kline, 2004). The comparative fit index (CFI) ranges from 0 to 1, and large numbers indicate better fit. It has been suggested that a CFI value above .90 (close to or higher than .95) indicates good fit (Hu & Bentler, 1999). Finally, for the root mean square error of approximation (RMSEA), a value  $\leq .05$  indicates good fit, and values between .05 and .08 suggest reasonable error of approximation (Browne and Cudeck, 1993).

When all of the theory-consistent items were included in the model simultaneously, the fit was suboptimal ( $\chi^2 = 415.14$ ,  $df = 20$ ,  $p < .0001$ , RMSEA = 0.257, CFI = 0.77). Given that some of the items were very similar in specific wording and content and highly correlated (e.g., “I worry that a recurrence of cancer would cause me to die/threaten my life,”  $r = .86$ ), we removed redundant items to improve model fit, retaining the highest loading item in each case. The resulting five-item model resulted in improved, but still not ideal fit ( $\chi^2 = 108.92$ ,  $df = 5$ ,  $p < .0001$ , RMSEA = 0.263, CFI = 0.83;  $\Delta\chi^2(15) = 306.22$ ,  $p < .0001$ ). We next permitted a correlation between our two discrepancy items, which again improved fit ( $\chi^2 = 16.02$ ,  $df = 4$ ,  $p < .01$ , RMSEA = 0.100, CFI = 0.98;  $\Delta\chi^2(1) = 92.90$ ,  $p < .0001$ ); however, we found that an even more parsimonious model, with only one discrepancy item, had the best fit. The resulting four-item fear of recurrence model included the following items: “I am worried or anxious about the possibility of recurrence,” “I worry that a

recurrence of cancer would cause me to die,” “How often do you think about the possibility of cancer recurrence?” and the perceived-objective risk estimate discrepancy item (see Figure 3.1). This model had exceptional fit ( $\chi^2 = 0.26$ ,  $df = 1$ ,  $p = .61$ , RMSEA = 0.000, CFI = 1.00;  $\Delta\chi^2(3) = 15.76$ ,  $p < .01$ ;  $\omega = .643$ ). We now turn to examining whether the latent fear of recurrence factor onto which these items loaded was a significant predictor of cancer-relevant behavioral outcomes.

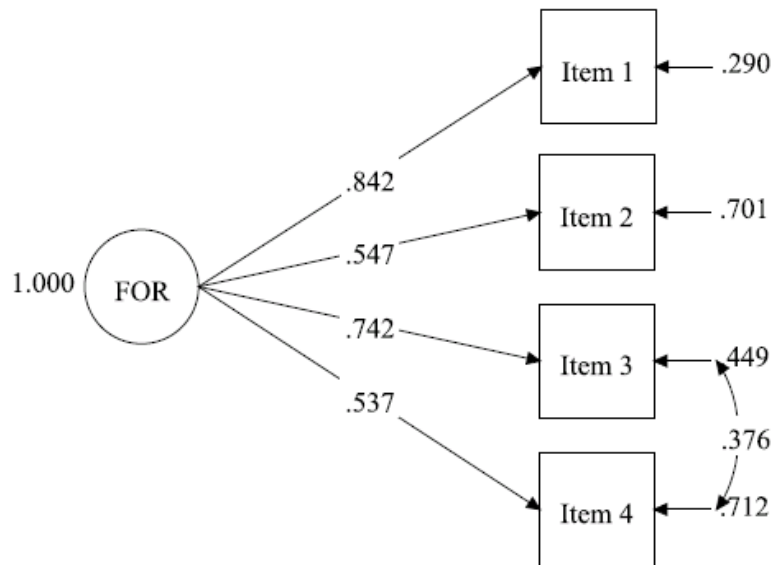


Figure 3.1 Theory-based fear of recurrence model.

All item loadings are statistically significant ( $p < .001$ ). Item 1: “How often do you think about the possibility of cancer recurrence?” Item 2: Discrepancy between perceived risk and an objective estimate of risk. Item 3: “I am worried or anxious about the possibility of cancer recurrence.” Item 4: “I worry that a recurrence of cancer would cause me to die.” FOR: Fear of recurrence factor.

### **3.3 Fear of Recurrence as a Predictor of Behavioral Outcomes**

Utilizing structural regression, a method of regression that can be used with both latent and measured variables, we tested our hypothesis that fear of recurrence is associated with relevant behavioral outcomes. To do so, we added each behavioral outcome variable to our fear of recurrence model, with the outcome regressed on the fear of recurrence latent factor. As detailed in Table 3.3, we found that the latent factor of fear of recurrence was a significant predictor of mental health outcomes (mental health counseling, psychotropic medications, and receiving a recommendation to receive mental health treatment since diagnosis), encounters with oncology medical providers (the occurrence of phone calls and visits to oncology providers' offices within the past three months, the number of phone calls and visits to oncology providers in the past year), flourishing (negatively related), disengagement from life activities, physical self-examination, and functional impairment. Fear of recurrence, however, did not predict significantly encounters with primary care physicians (calls/visits) nor engagement in life activities.

Table 3.3 Fear of Recurrence as a Predictor of Behavioral Outcomes

Behavioral outcomes	<i>b</i>	95% CI	<i>SE</i>	<i>OR</i>	95% CI	<i>p</i> -value
MH counseling <sup>a</sup>	0.57	0.20 - 0.94	0.22	1.77	1.22 - 2.55	.01
MH medication <sup>a</sup>	0.77	0.40 - 1.14	0.23	2.16	1.49 - 3.13	<.01
MH recommendation <sup>a</sup>	1.08	0.59 - 1.56	0.30	2.94	1.81 - 4.78	<.001
Recent oncology visit <sup>a</sup>	0.61	0.28 - 0.99	0.20	1.84	1.32 - 2.54	<.01
Annual oncology visits <sup>b</sup>	2.63	1.48 - 3.78	0.70	--	--	<.001
Recent oncology call <sup>a</sup>	0.82	0.37 - 1.27	0.27	2.26	1.44 - 3.55	<.01
Annual oncology calls <sup>b</sup>	1.14	0.50 - 1.79	0.39	--	--	<.01
Recent PCP visit <sup>a</sup>	-0.01	-0.32 - 0.31	0.19	0.99	0.73 - 1.36	.97
Annual PCP visits <sup>b</sup>	0.16	0.00 - 0.32	0.10	--	--	.10
Recent PCP call <sup>a</sup>	0.35	0.02 - 0.67	0.20	1.42	1.02 - 1.96	.08
Annual PCP calls <sup>b</sup>	0.69	-0.04 - 1.41	0.44	--	--	.12
Flourishing	-0.45	-0.60 - -0.31	0.09	--	--	<.001
Engagement	0.12	-0.21 - 0.44	0.20	--	--	.56
Disengagement <sup>b</sup>	0.51	0.24 - 0.79	0.17	--	--	<.01
Self-examination	0.39	0.19 - 0.59	0.12	--	--	<.01
Functional impairment	0.63	0.63 - 0.79	0.08	--	--	<.001

<sup>a</sup>These outcomes are dichotomous; as such, odds ratios are also provided for these outcomes.

<sup>b</sup>These outcomes are count variables.

### 3.3.1 Controlling for Other Relevant Factors

The fear of recurrence latent factor was associated with younger age ( $r = -.29$ ,  $SE = .06$ ,  $p < .001$ ), more advanced stage ( $r = .18$ ,  $SE = .06$ ,  $p < .01$ ), and less time since diagnosis ( $r = -.14$ ,  $SE = .06$ ,  $p = .02$ ). It was not associated with the objective estimate of risk ( $r = -.05$ ,  $SE = .07$ ,  $p = .48$ ). We were particularly interested in any potential effect of time since treatment on our outcomes. We re-ran our behavioral outcome regressions controlling for time since diagnosis and found that each of the originally significant relationships with fear of recurrence remained significant when including time since diagnosis as a covariate. For exploratory purposes, we also

included age and stage as covariates and found that fear of recurrence remained a significant predictor of all of the originally significant behavioral outcomes, with the exception of mental health treatment, which was better accounted for by younger age ( $b = -0.04, SE = 0.01, p < .001$ ) and the occurrence of an oncology visit in the past three months, which was better accounted for by more advanced stage ( $b = 0.26, SE = 0.09, p < .01$ ) and less time since diagnosis ( $b = -0.20, SE = 0.04, p < .001$ ).

### **3.3.2 Further Assessment of the Risk Discrepancy Item**

The perceived risk of recurrence variable had more variability than the objective estimate of risk variable. Therefore, we examined whether a transformed version of the discrepancy item, computed with z-scores of the items, performed differently. The z-score-based discrepancy score was highly correlated with the original discrepancy score ( $r = .91, p < .001$ ). We next re-specified our theory-based fear of recurrence factor replacing the original discrepancy item with the z-score-based discrepancy item. The fit of these models was similar ( $\Delta\chi^2(0) = 0.20$ ). We also re-ran each of the behavioral outcome regressions and found no change in significance using the z-score-based discrepancy item in the fear of recurrence model.

### **3.3.3 Moderating Role of Time since Treatment**

We next evaluated whether any of the relationships between fear of recurrence and the behavioral outcomes discussed above were moderated by time since diagnosis. We found that time since diagnosis did not moderate fear of recurrence's relationship with any of the following: the occurrence of calls or visits to oncology or primary care physicians in the past three months, psychotropic medication use or receipt of a

recommendation to seek mental health treatment since diagnosis, the number of calls to oncology and primary care providers in the past year, the number of visits to primary care providers in the past year, disengagement, engagement, flourishing, or functional impairment.

We found that the relationships between fear of recurrence and three behavioral outcomes were moderated by time since diagnosis: number of oncology visits in the past year, mental health counseling since diagnosis, and self-examination. We found that, when regressing number of annual oncology visits on fear of recurrence, time since diagnosis, and their product, time since diagnosis ( $b = -0.24$ ,  $SE = 0.04$ ,  $p < .001$ ), fear of recurrence ( $b = 1.23$ ,  $SE = 0.15$ ,  $p < .001$ ), and the *fear of recurrence x time since diagnosis* interaction ( $b = -0.19$ ,  $SE = 0.10$ ,  $p < .05$ ) were each significant predictors of number of oncology visits in the past year. To further probe this interaction, we calculated and plotted simple slopes using procedures outlined by Preacher, Curran, and Bauer (2006). We plotted the relationship between fear of recurrence and annual oncology visits at three levels of the moderator: one, four, and seven years since diagnosis. We found that the relationship between fear of recurrence and annual oncology visits was significant at one year since diagnosis ( $p < .0001$ ) but not at four ( $p = .11$ ) and seven years since diagnosis ( $p = .84$ ; see Figure 3.2). This suggests the effect of fear of recurrence on increased oncology visits is driven by those individuals who were more recently diagnosed with breast cancer.

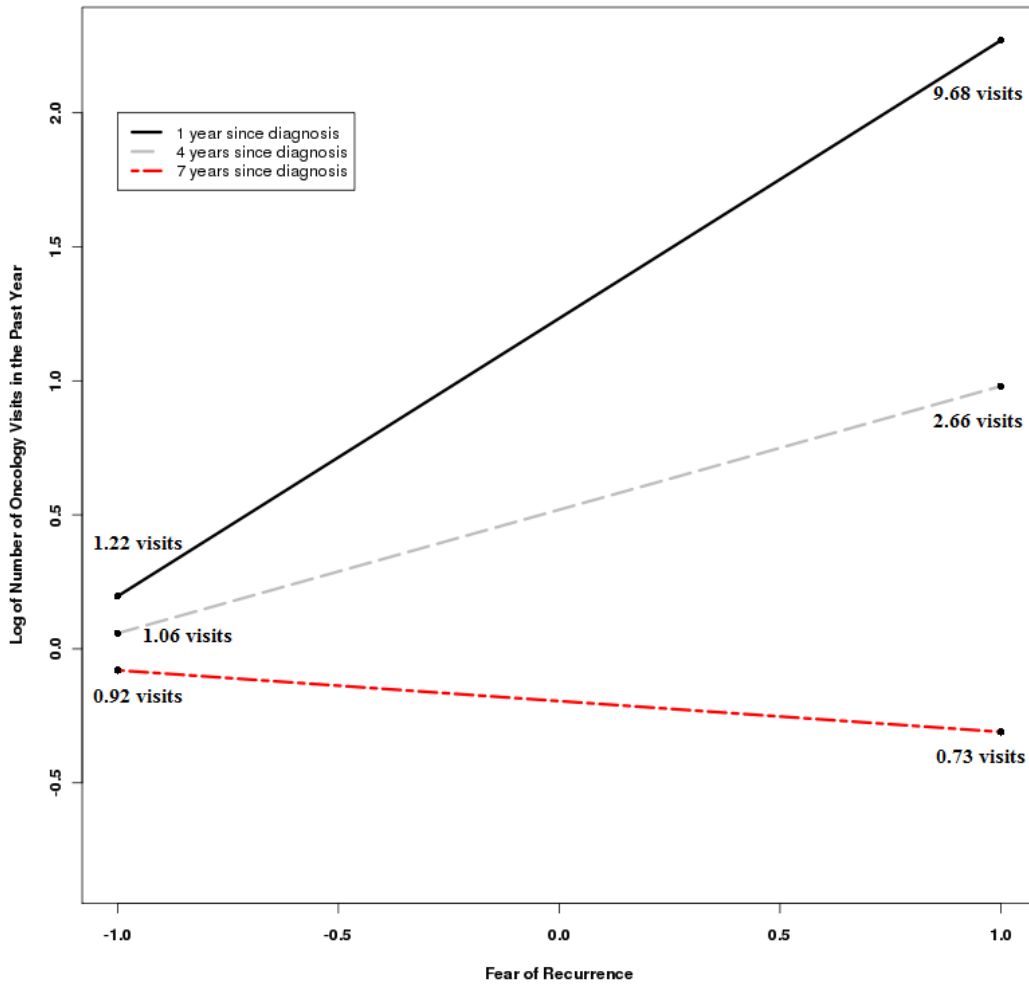


Figure 3.2 Time since diagnosis moderates the relationship between fear of recurrence and oncology visits in the past year.

Data are plotted for  $+1/-1$  *SD* from the mean for fear of recurrence. Three levels of the moderator are shown: one, four, and seven years since diagnosis. The relationship between fear of recurrence and annual oncology visits is significant only at one year since diagnosis ( $p < .0001$ ).

When regressing mental health counseling on fear of recurrence, time since diagnosis, and their product, we found that time since diagnosis ( $b = -0.04$ ,  $SE = 0.09$ ,  $p = .67$ ) and fear of recurrence ( $b = -0.32$ ,  $SE = 0.30$ ,  $p = .28$ ) were not significant, but the *fear of recurrence x time since diagnosis* interaction ( $b = 0.23$ ,  $SE = 0.09$ ,  $p = .01$ ) was a significant predictor of mental health counseling. When we plotted simple slopes, we found that the relationship between fear of recurrence and mental health counseling was significant at four ( $p < .01$ ) and seven years since diagnosis ( $p < .01$ ) but not at one year since diagnosis ( $p = .67$ ; see Figure 3.3). This suggests the effect between fear of recurrence and mental health counseling is not apparent among those recently diagnosed with breast cancer, whereas the relationship is apparent later in survivorship.

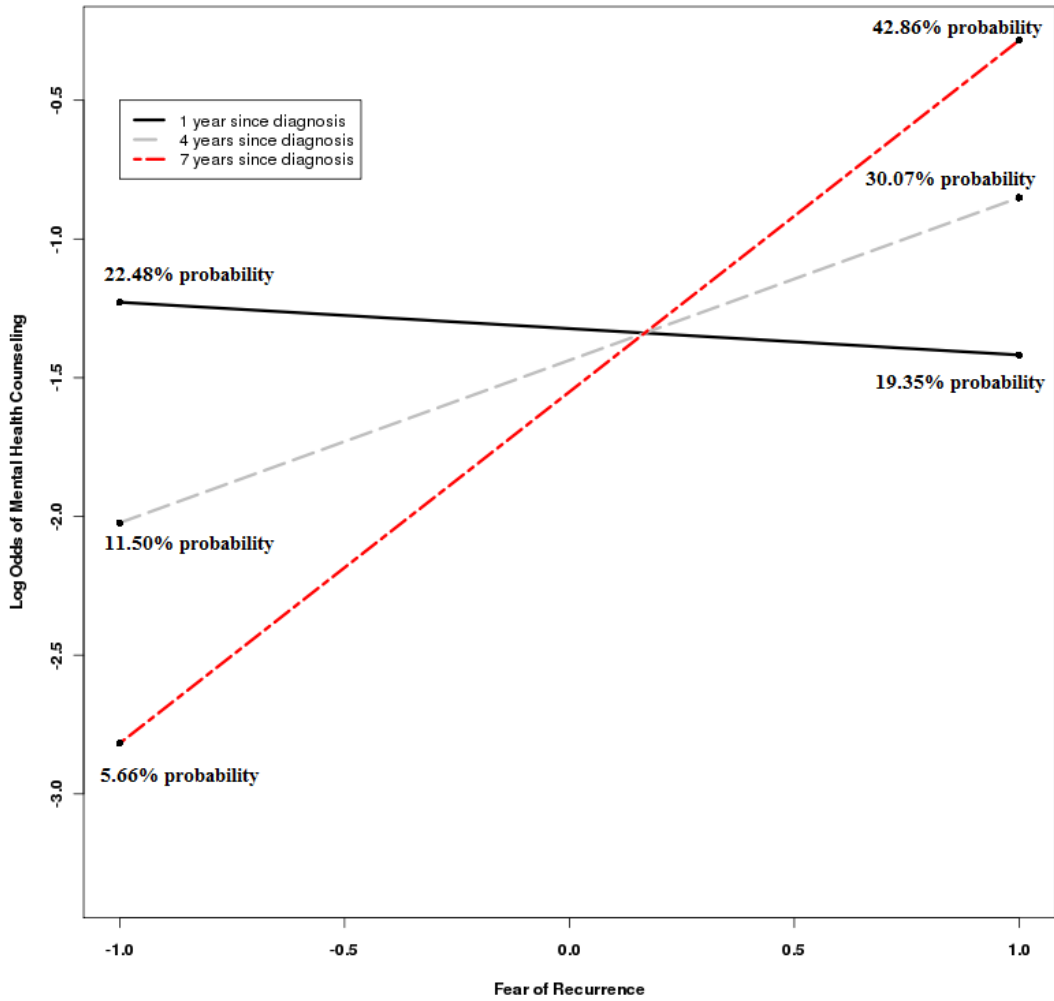


Figure 3.3 Time since diagnosis moderates the relationship between fear of recurrence and mental health counseling.

Data are plotted for  $+1/-1$  *SD* from the mean for fear of recurrence. Three levels of the moderator are shown: one, four, and seven years since diagnosis. The relationship between fear of recurrence and mental health counseling is significant only at four and seven years since diagnosis ( $p < .01$ ).

Finally, when regressing self-examination on fear of recurrence, time since diagnosis, and their product, we found that time since diagnosis ( $b = 0.01$ ,  $SE = 0.04$ ,  $p = .73$ ) and fear of recurrence ( $b = -0.14$ ,  $SE = 0.17$ ,  $p = .43$ ) were not significant, but the *fear of recurrence x time since diagnosis* interaction ( $b = 0.12$ ,  $SE = 0.04$ ,  $p < .01$ ) was a significant predictor of self-examination. When we plotted simple slopes, we again found that the relationship between fear of recurrence and self-examination was significant at four ( $p < .001$ ) and seven years since diagnosis ( $p < .0001$ ) but not at one year since diagnosis ( $p = .92$ ; see Figure 3.4). This suggests the effect between fear of recurrence and increased physical self-examination is not apparent among those recently diagnosed with breast cancer, whereas the relationship is apparent later in survivorship.

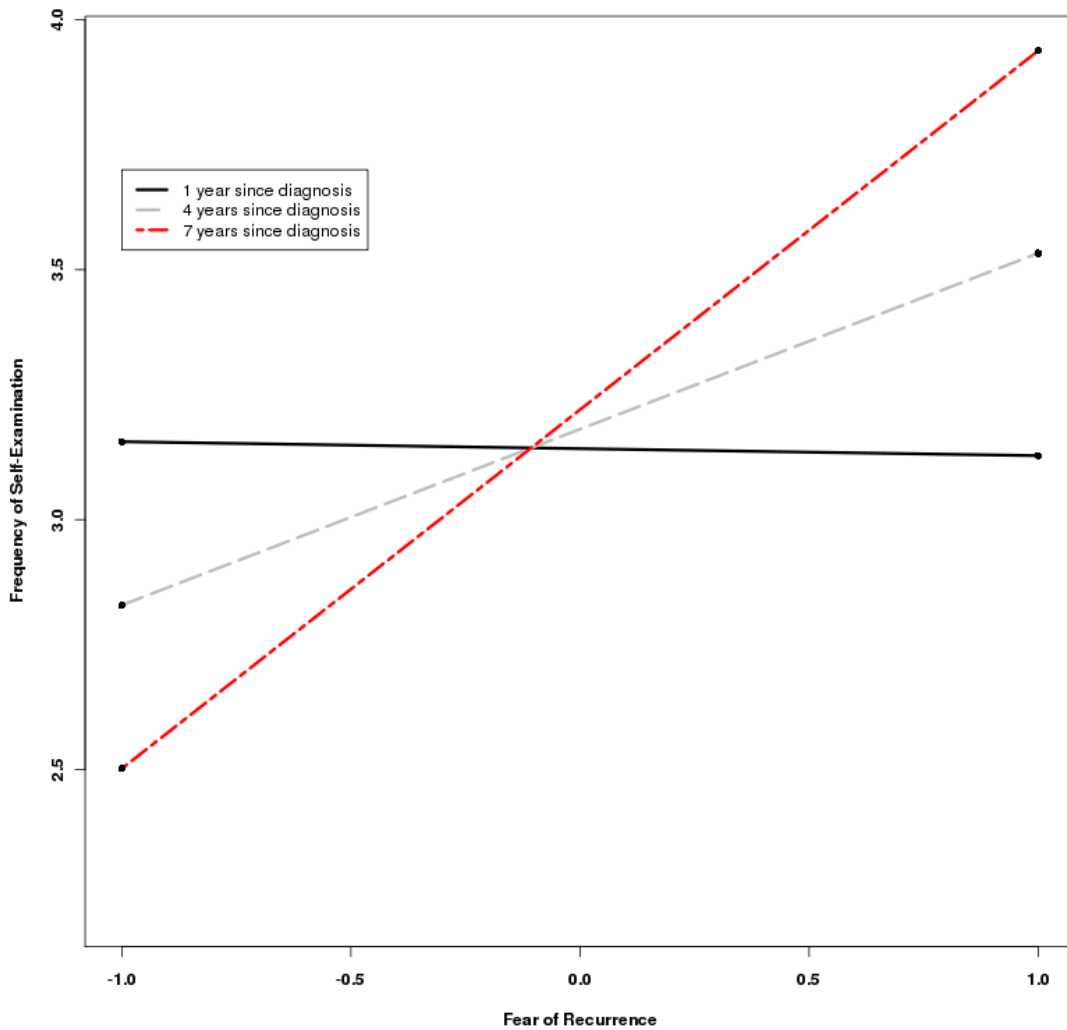


Figure 3.4 Time since diagnosis moderates the relationship between fear of recurrence and self-examination.

Data are plotted for  $+1/-1$  *SD* from the mean for fear of recurrence. Three levels of the moderator are shown: one, four, and seven years since diagnosis. The relationship between fear of recurrence and self-examination is significant only at four and seven years since diagnosis ( $p < .001$ ).

### 3.3.4 Moderating Role of Acceptance

We predicted that acceptance (i.e., willingness to experience unwanted emotions and thoughts, ability to be in the present moment, commitment to values-directed actions in spite of negative psychological experiences) would attenuate the negative effects of fear of recurrence on functional impairment and goal-striving variables (i.e., engagement, disengagement, flourishing). The latent fear of recurrence factor was a significant predictor of functional impairment, flourishing, and disengagement, so we assessed for the potential moderating role of acceptance on each of these relationships. We found that the *fear of recurrence x acceptance* interaction was not a significant predictor of disengagement or flourishing; however, the *fear of recurrence x acceptance* interaction was a significant predictor of functional impairment.

More specifically, in our model regressing flourishing on fear of recurrence, acceptance, and their product (based on the centered predictors), acceptance was a significant predictor ( $b = 0.55, SE = 0.07, p < .001$ ), fear of recurrence was no longer a significant predictor ( $b = -0.09, SE = 0.05, p = .10$ ), and, of central interest, the *fear of recurrence x acceptance* interaction was not a significant predictor of flourishing ( $b = 0.04, SE = 0.09, p = .66$ ).

Our disengagement model yielded a similar pattern of results; when regressing disengagement on fear of recurrence, acceptance, and their product, acceptance was a significant predictor ( $b = -0.53, SE = 0.08, p < .001$ ), but neither fear of recurrence ( $b$

= 0.16,  $SE = 0.12$ ,  $p = .17$ ), nor the *fear of recurrence x acceptance* interaction ( $b = 0.11$ ,  $SE = 0.08$ ,  $p = .14$ ) was a significant predictor of disengagement.

Finally, in our functional impairment model, when regressing impairment on fear of recurrence, acceptance, and their product, acceptance ( $b = -0.29$ ,  $SE = 0.05$ ,  $p < .001$ ), fear of recurrence ( $b = 0.24$ ,  $SE = 0.04$ ,  $p < .001$ ), and the *fear of recurrence x acceptance* interaction ( $b = -0.26$ ,  $SE = 0.04$ ,  $p < .001$ ) were each significant predictors of functional impairment. To further probe this interaction, we again calculated and plotted simple slopes using procedures outlined by Preacher et al. (2006). As predicted, we found that higher levels of acceptance attenuated the negative effects of fear of recurrence on functional impairment. For those low in acceptance, fear of recurrence had a positive relationship with functional impairment ( $p < .0001$ ), whereas, for those high in acceptance, there was no association between fear of recurrence and functional impairment ( $p = .95$ ; see Figure 3.5).

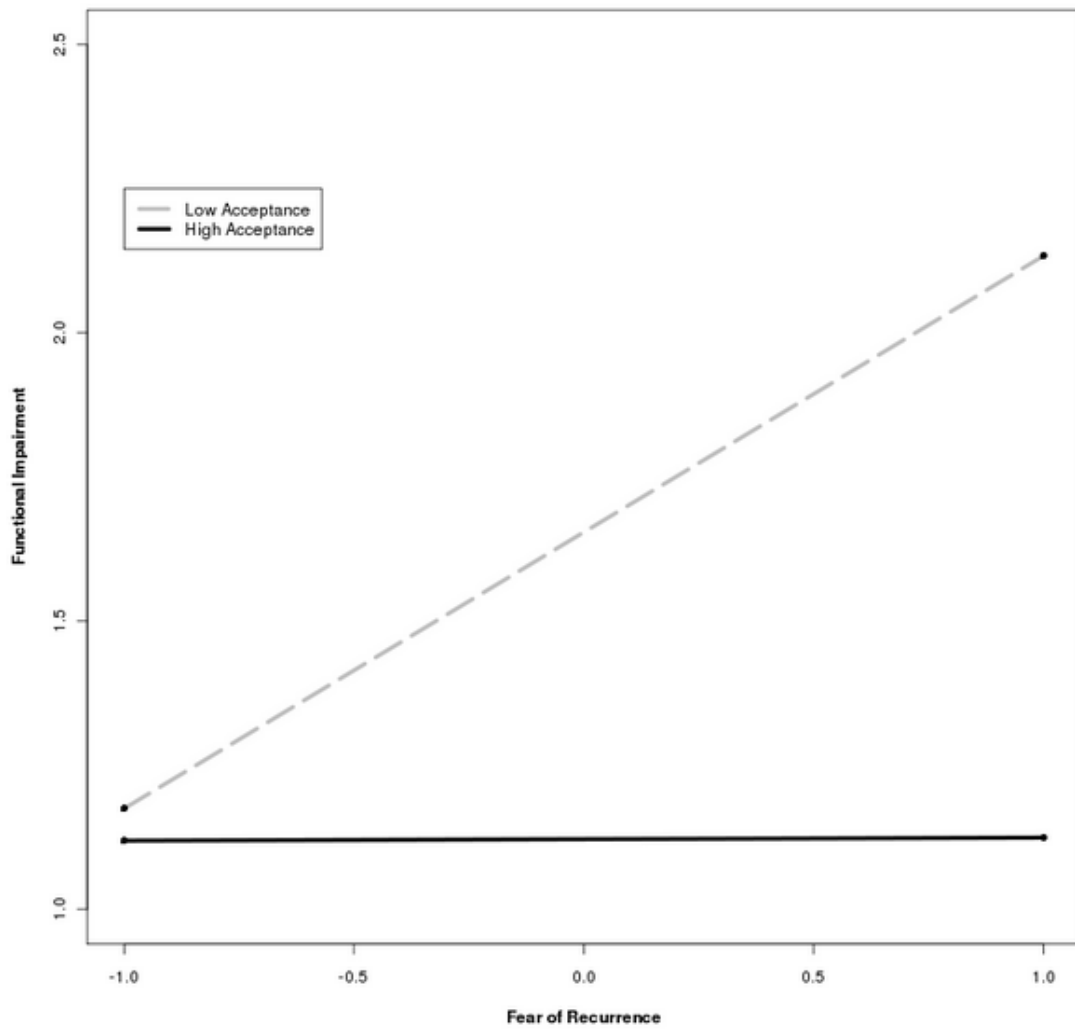


Figure 3.5 Acceptance moderates the relationship between fear of recurrence and functional impairment.

Data are plotted for  $+1/-1$  *SD* from the mean for both fear of recurrence and acceptance. Only the low acceptance slope is significant ( $p < .001$ ).

### 3.3.5 Moderating Role of Avoidance

With regard to avoidance, we predicted that the relationship between fear of recurrence and physical self-examination, as well as the relationship between fear of recurrence and health care utilization, would be moderated by an avoidant response style. As described earlier, the latent fear of recurrence factor was a significant predictor of the following health care utilization variables: oncology office visits and calls in the past three months (yes/no) and past year (number). Therefore, we evaluated the potential moderating role of acceptance for each of these outcomes. We found that the *fear of recurrence x avoidance* interaction was not a significant predictor of any of the predicted outcomes.

With regard to self-examination, fear of recurrence was a significant predictor ( $b = 0.28, SE = 0.10, p < .01$ ), but neither avoidance ( $b = -0.01, SE = 0.08, p = .86$ ), nor the *fear of recurrence x avoidance* interaction ( $b = -0.12, SE = 0.11, p = .25$ ) were significant predictors of this outcome.

With regard to the occurrence of an oncology office visit in the past three months, fear of recurrence was a significant predictor ( $b = 0.43, SE = 0.15, p < .01$ ), but neither avoidance ( $b = 0.013, SE = 0.109, p = .91$ ), nor the *fear of recurrence x avoidance* interaction ( $b = -0.05, SE = 0.12, p = .70$ ) were significant predictors of this health care outcome.

With regard to the number of oncology office visit in in the past year, fear of recurrence was a significant predictor ( $b = 1.00, SE = 0.09, p < .001$ ), and avoidance was a significant predictor ( $b = -0.18, SE = 0.08, p = .02$ ), but the *fear of recurrence x*

*avoidance* interaction ( $b = 0.06$ ,  $SE = 0.08$ ,  $p = .46$ ) was not a significant predictor of this health care outcome.

With regard to the occurrence of a call to an oncology office in the past three months, again, fear of recurrence was a significant predictor ( $b = 0.55$ ,  $SE = 0.19$ ,  $p < .01$ ), but neither avoidance ( $b = 0.01$ ,  $SE = 0.17$ ,  $p = .98$ ), nor the *fear of recurrence x avoidance* interaction ( $b = 0.01$ ,  $SE = 0.17$ ,  $p = .96$ ) were significant predictors of this health care outcome.

With regard to the number of calls to an oncology office in the past year, fear of recurrence was a significant predictor ( $b = 0.69$ ,  $SE = 0.18$ ,  $p < .001$ ), but again, neither avoidance ( $b = -0.05$ ,  $SE = 0.17$ ,  $p = .80$ ) nor the *fear of recurrence x avoidance* interaction ( $b = 0.09$ ,  $SE = 0.17$ ,  $p = .61$ ) were significant predictors of this health care outcome.

### **3.3.6 Evaluation of Non-Linear Effects**

We also explored the possibility that fear of recurrence might have non-linear relationships with behavioral outcomes. We were most interested in potential non-linear effects between fear of recurrence and health care utilization and positive health changes made since cancer (e.g., healthy lifestyle changes such as improving diet and exercise).

With regard to health care utilization, we specified a model including both linear and quadratic fear of recurrence effects predicting number of calls and visits to oncology providers in the past year. We found that the quadratic effect was not significant for calls to oncology providers ( $b = 0.36$ ,  $SE = 0.42$ ,  $p = .39$ ); however, the

quadratic effect was significant for number of visits to oncology providers in the past year ( $b = 0.63, SE = 0.01, p < .001$ ). This suggests that the relationship between fear of recurrence and oncology office visits may best be viewed as non-linear, with fewer oncology visits at average levels of fear of recurrence and more visits at extreme levels of fear of recurrence. However, when we tried to replicate this finding with the FCRI total score or the CARS overall fear scale, we found that the quadratic effect of fear of recurrence was not significant in the prediction of oncology visits.

We also explored the possibility of a non-linear effect of fear of recurrence on self-examination; however, we found that the quadratic effect was non-significant ( $b = 0.01, SE = 0.16, p = .97$ ).

In addition to these behavioral outcomes that we expected fear of recurrence to predict, we also explored the relationship between fear of recurrence and positive changes, for which there was less clear evidence. We found that fear of recurrence was not associated significantly with making positive life adjustments ( $b = -0.045, SE = 0.083, p = .59$ ). In addition to specifying a linear relationship, we also tested for a quadratic relationship between fear of recurrence and positive changes; however, again, we found no significant relationship ( $b = -0.050, SE = 0.106, p = .64$ ). For exploratory purposes, we also tested for potential moderating effects of acceptance and avoidance, but we found that neither the *fear of recurrence x acceptance* interaction term ( $p = .17$ ) nor the *fear of recurrence x avoidance* interaction term ( $p = .50$ ) were significant predictors of positive changes.

### **3.4 Fear of Recurrence and Theoretically-related Constructs**

After developing an understanding of the fear of recurrence construct and its relation to behavioral outcomes, we used bifactor modeling and ESEM to test our hypotheses about the relations between fear of recurrence and other theoretically-related constructs. Each of these structural equation modeling methods offer significant advantages over traditional CFA. For example, in traditional CFA, an indicator (item) can load on one, and only one, factor while its loading on other factors is fixed to zero. By contrast, in ESEM, cross-factor loadings are also estimated instead of being fixed to be zero, taking into account that, while an indicator may load most on to one factor, its loading is unlikely to be zero for another factor, especially when those factors are related. Thus, ESEM models more realistically reflect the relationships between items in a latent variable modeling framework (Asparouhov & Muthén, 2009).

Bifactor models, also known as general-specific or nested models, offer another type of flexibility that is particularly useful when working with multifaceted constructs or when one is interested in assessing multiple facets of the same construct (Chen, Hayes, Carver, Laurenceau, & Zhang, 2012). In a bifactor model, every item is allowed to load on a general factor that is presumed to underlie all of the items—typically a conceptually broad factor (e.g., extraversion). Simultaneously, items may also load on conceptually narrower, specific factors (e.g., warmth, gregariousness, activity, etc.). Therefore, bifactor models allow one to assess effects involving a general factor, which represents what is common to all the facets, as well as effects

involving a specific facet, or, what is left when the commonality across items is accounted for (Chen et al., 2012).

We used ESEM to demonstrate the relations between of fear of recurrence and each of the following constructs: anxious apprehension, uncertainty intolerance, anxious arousal, anhedonic depression, and optimism. We used ESEM because each of these constructs are generally understood to have relatively non-complex (e.g., unitary) structures and to explore the relations between these constructs and fear of recurrence faithfully. By using ESEM, we allowed for non-zero cross-factor loadings, which took into account the fact that, while fear of recurrence items may load most heavily on one factor, their loadings were unlikely to be zero for another similar construct (see Figures 3.6 through 3.8 for a comparison of CFA versus ESEM modeling). We predicted that fear of recurrence would have some degree of overlap with each of these other constructs but also emerge as a distinct construct. Therefore, we predicted that, when modeling fear of recurrence with each of the aforementioned constructs, the data would better fit a two-factor ESEM model than a one-factor ESEM model (see Figures 3.7 and 3.8 for a comparison).

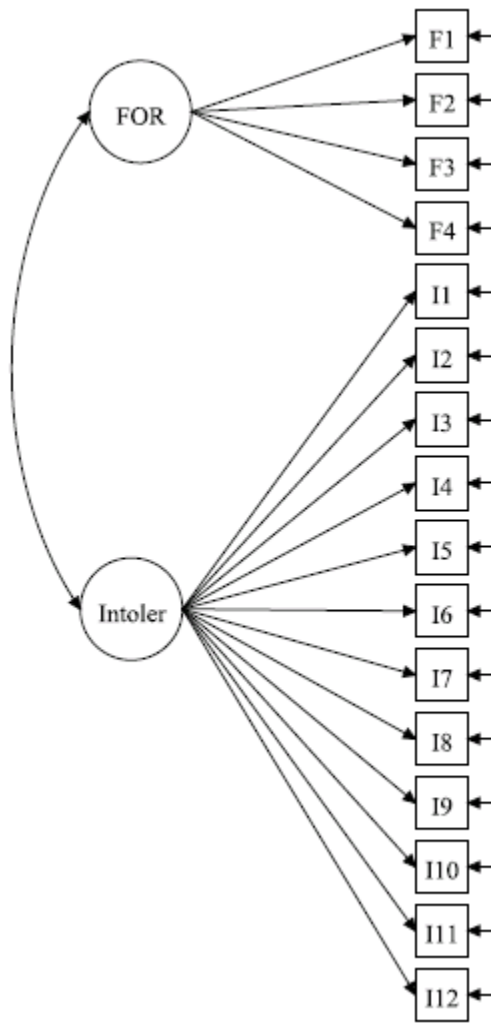


Figure 3.6 Illustration of a traditional CFA model.

Each item loads onto one and only one factor, in this case fear of recurrence or uncertainty intolerance (see Figure 3.8 for a comparison to an ESEM model). F1-F4: Fear of recurrence items. I1-I12: Uncertainty intolerance items. FOR: Fear of recurrence factor. Intoler: Uncertainty intolerance factor.

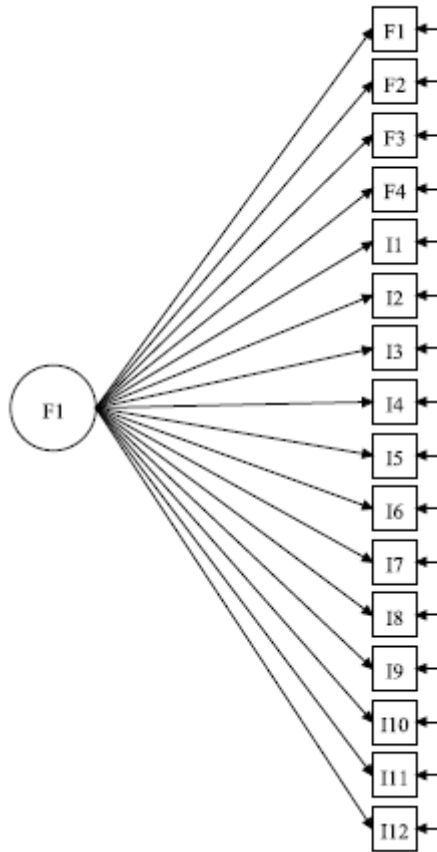


Figure 3.7 Illustration of a one-factor model.

We evaluated whether fear of recurrence items best loaded onto a one-factor model or a two-factor model with items of a similar construct, in this case uncertainty intolerance (see Figure 3.8 for a two-factor, ESEM comparison). F1-F4: Fear of recurrence items. I1-I12: Uncertainty intolerance items. F1: Factor 1.

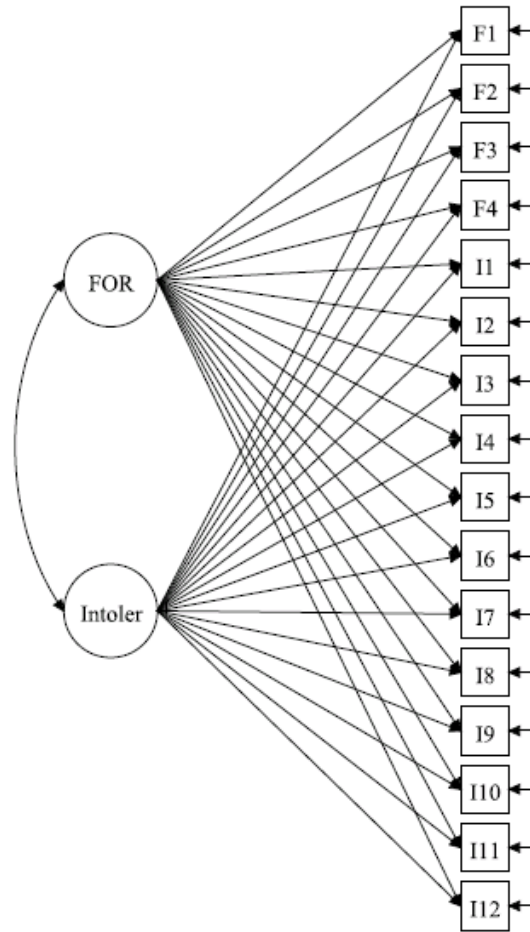


Figure 3.8 Illustration of a two-factor ESEM model.

Each item can load onto multiple factors. We evaluated whether fear of recurrence items best loaded onto a one-factor model or a two-factor model with items of a similar construct, in this case uncertainty intolerance (see Figure 3.7 for a one-factor model comparison). This modeling approach is expected to reflect relationships between variables more faithfully than traditional CFA (see Figure 3.6 for a two-factor, CFA comparison). F1-F4: Fear of recurrence items. I1-I12: Uncertainty intolerance items. FOR: Fear of recurrence factor. Intoler: Uncertainty intolerance factor.

### 3.4.1 Anxious Apprehension, Uncertainty Intolerance, and Anxious Arousal

We began by examining the three anxiety-related constructs that we expected to be associated with but distinguishable from fear of recurrence. Consistent with our hypothesis, we found that a two-factor model of fear of recurrence and anxious apprehension items fit the data significantly better ( $\chi^2 = 586.12$ ,  $df = 150$ ,  $p < .0001$ , RMSEA = 0.098, CFI = 0.89) than a one-factor model ( $\chi^2 = 846.16$ ,  $df = 169$ ,  $p < .0001$ , RMSEA = 0.116, CFI = 0.82;  $\Delta\chi^2(19) = 260.04$ ,  $p < .0001$ ). Although an examination of other constructs' measurement scales is beyond the scope of this study, it is worth noting that we found that model fit improved further, and the resulting scale loadings were more easily interpretable, with the addition of a third factor resulting in a three-factor model in which fear of recurrence items loaded heavily onto one factor and anxious apprehension items loaded heavily onto two factors—one comprised of reverse-worded items, and one comprised of positively-worded items ( $\chi^2 = 396.64$ ,  $df = 132$ ,  $p < .0001$ , RMSEA = 0.082, CFI = 0.93;  $\Delta\chi^2(18) = 189.48$ ,  $p < .0001$ ). We predicted that fear of recurrence and anxious apprehension would have a moderate strength correlation when allowing for cross-loadings. We found that fear of recurrence had a moderate-to-strong correlation with a factor representing positively-worded anxious apprehension items ( $r = .41$ ,  $p < .001$ ) and weak-to-moderate correlation with a factor representing negatively-worded anxious apprehension items ( $r = .23$ ,  $p = 0.02$ ; see Figure 3.9).

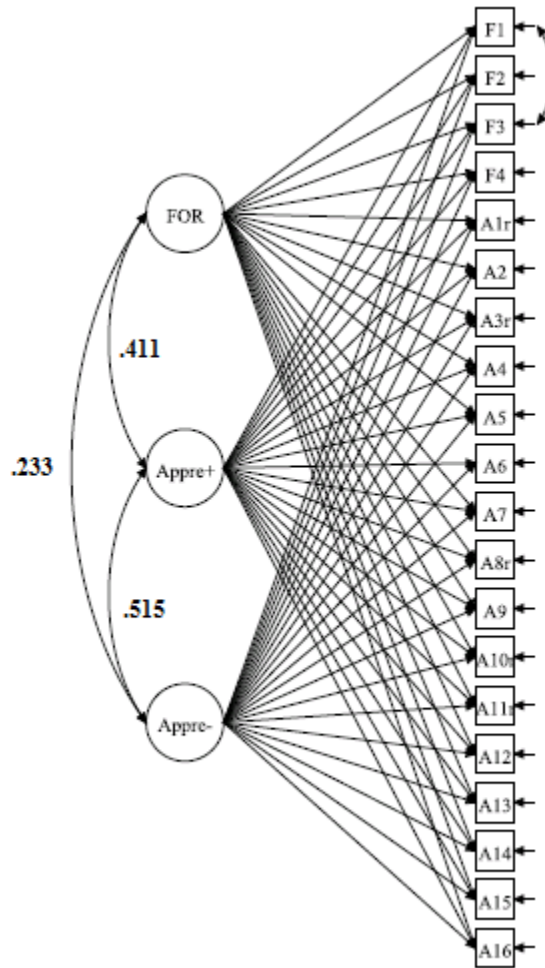


Figure 3.9 ESEM model with fear of recurrence and anxious apprehension.

Positively- and negatively worded anxious apprehension items each loaded significantly on their own factors. Correlations shown are significant ( $p < .05$ ). F1-F4: Fear of recurrence items. A1-A16: Anxious apprehension items. FOR: Fear of recurrence factor. Appre+: Positively-worded anxious apprehension factor. Appre-: Negatively-worded anxious apprehension factor.

Likewise, in our uncertainty intolerance and fear of recurrence ESEM model, we found that a two-factor model fit the data significantly better ( $\chi^2 = 370.01$ ,  $df = 88$ ,  $p < .0001$ , RMSEA = 0.103, CFI = 0.87) than a one-factor model ( $\chi^2 = 667.24$ ,  $df = 104$ ,  $p < .0001$ , RMSEA = 0.134, CFI = 0.74;  $\Delta\chi^2(16) = 297.23$ ,  $p < .0001$ ). Although the IUS-12 has two subscales, when we explored a three-factor ESEM model, we found that the split of uncertainty intolerance items did not conform to these subscales. We predicted that fear of recurrence and uncertainty intolerance would have a moderate strength correlation when allowing for cross-loadings. We found that fear of recurrence had a moderate-to-strong correlation with uncertainty intolerance ( $r = .45$ ,  $p < .001$ ; see Figure 3.10).

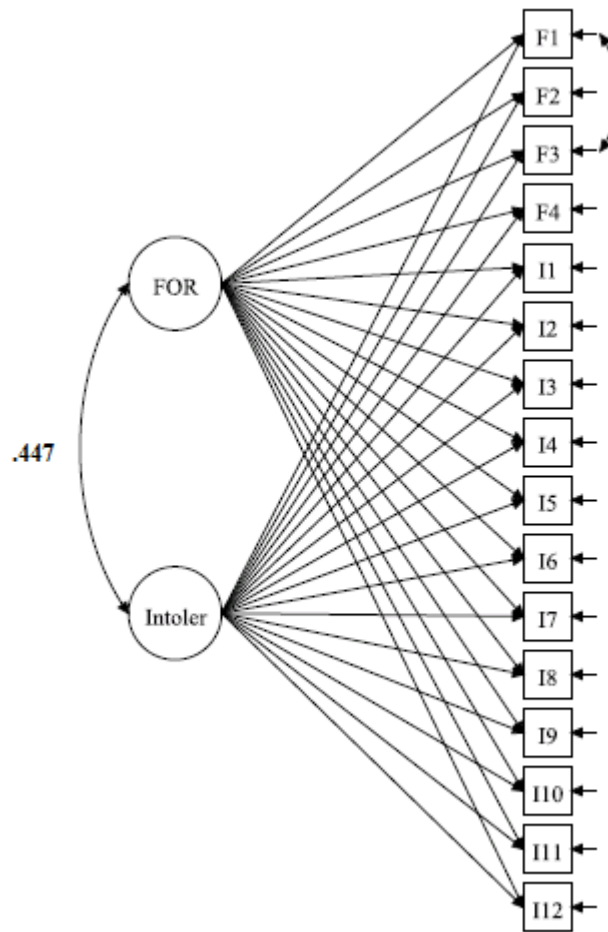


Figure 3.10 ESEM model with fear of recurrence and uncertainty intolerance.

Correlation shown is significant ( $p < .001$ ). F1-F4: Fear of recurrence items. I1-I12: Uncertainty intolerance items. FOR: Fear of recurrence factor. Intoler: Uncertainty intolerance factor.

Our third theoretically-related construct, anxious arousal, demonstrated a similar pattern of results. Again, we found that a two-factor model fit the data significantly better ( $\chi^2 = 493.21$ ,  $df = 168$ ,  $p < .001$ , RMSEA = 0.080, CFI = 0.83) than a one-factor model ( $\chi^2 = 861.22$ ,  $df = 189$ ,  $p < .0001$ , RMSEA = 0.109, CFI = 0.65;  $\Delta\chi^2(21) = 368.01$ ,  $p < .0001$ ). We predicted that fear of recurrence and anxious arousal would have a small correlation when allowing for cross-loadings. We found that fear of recurrence had a moderate-sized correlation with anxious arousal ( $r = .30$ ,  $p < .01$ ; see Figure 3.11).

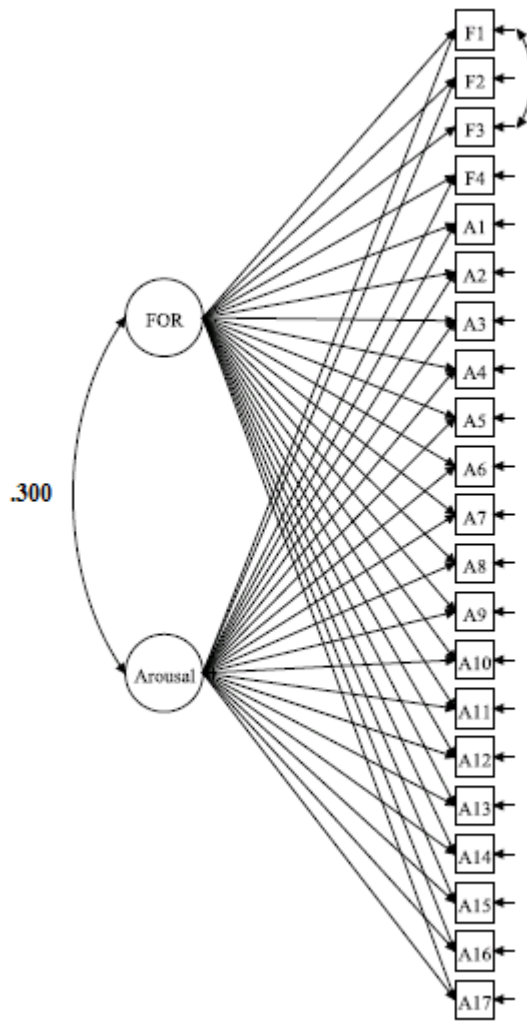


Figure 3.11 ESEM model with fear of recurrence and anxious arousal.

Correlation shown is significant ( $p < .05$ ). F1-F4: Fear of recurrence items. A1-A17: Anxious arousal items. FOR: Fear of recurrence factor. Arousal: Anxious arousal factor.

### 3.4.1.1 Comparison of Correlations

We predicted that fear of recurrence would be characterized by more anxious apprehension and uncertainty intolerance than anxious arousal. To test this hypothesis, we specified a four-factor ESEM model including fear of recurrence, anxious apprehension, uncertainty intolerance, and anxious arousal as latent factors in order to examine the adjusted correlations (after allowing for cross-loading) between fear of recurrence and these other anxiety constructs and to directly compare the strength of the associations.

We found that a four-factor structure had less than adequate fit (again, likely due to reverse-worded anxious apprehension items), but items from the same scale hung together to comprise each of the expected latent factors (fear of recurrence, anxious arousal, etc.;  $\chi^2 = 2291.04$ ,  $df = 986$ ,  $p < .0001$ , RMSEA = 0.066, CFI = 0.83). The five-factor structure, which included the split of positively- and negatively-worded anxious apprehension items discussed previously, fit the data significantly better ( $\chi^2 = 1998.36$ ,  $df = 941$ ,  $p < .0001$ , RMSEA = 0.061, CFI = 0.86;  $\Delta\chi^2(45) = 292.68$ ,  $p < .0001$ ). Examining the full model, we found that fear of recurrence was associated most strongly with positively-worded anxious apprehension ( $r = .43$ ,  $p < .001$ ), followed by uncertainty intolerance ( $r = .35$ ,  $p < .001$ ), negatively-worded anxious apprehension ( $r = .24$ ,  $p < .001$ ), and anxious arousal ( $r = .23$ ,  $p < .001$ ).

ESEM models do not permit direct comparisons of correlations, so we specified an analogous CFA model to test whether these correlations were statistically different. It should be noted, however, that the CFA-based correlations were stronger

due to the limitations discussed previously (i.e., cross-factor loadings are set to zero). Utilizing bootstrapped standard errors, we found that the correlation between positively-worded anxious apprehension and fear of recurrence was significantly stronger than the correlation between anxious arousal and fear of recurrence ( $\Delta r = 0.169$ ,  $SE = 0.08$ ,  $p = .03$ ). Likewise, we found that the correlation between positively-worded anxious apprehension and fear of recurrence was significantly stronger than the correlation between negatively-worded anxious apprehension and fear of recurrence ( $\Delta r = 0.216$ ,  $SE = 0.08$ ,  $p = .01$ ). All other correlation differences were non-significant.

### **3.4.2 Anhedonic Depression and Optimism**

As with the previously tested anxiety constructs, we expected to see a better fitting two-factor structure than one-factor structure when examining fear of recurrence with anhedonic depression and optimism. Because of less theoretical overlap, we predicted that fear of recurrence would be more weakly associated with anhedonic depression and optimism than the other, aforementioned anxiety-related constructs.

With regard to anhedonic depression, we found that a two-factor structure ( $\chi^2 = 169.89$ ,  $df = 33$ ,  $p < .0001$ ,  $RMSEA = 0.118$ ,  $CFI = 0.92$ ) fit the data significantly better than a one-factor structure ( $\chi^2 = 353.04$ ,  $df = 43$ ,  $p < .0001$ ,  $RMSEA = 0.155$ ,  $CFI = 0.82$ ;  $\Delta\chi^2(10) = 183.15$ ,  $p < .0001$ ). However, contrary to our prediction, we found a relatively strong correlation between fear of recurrence and anhedonic depression ( $r = .44$ ,  $p < .001$ ; see Figure 3.12).

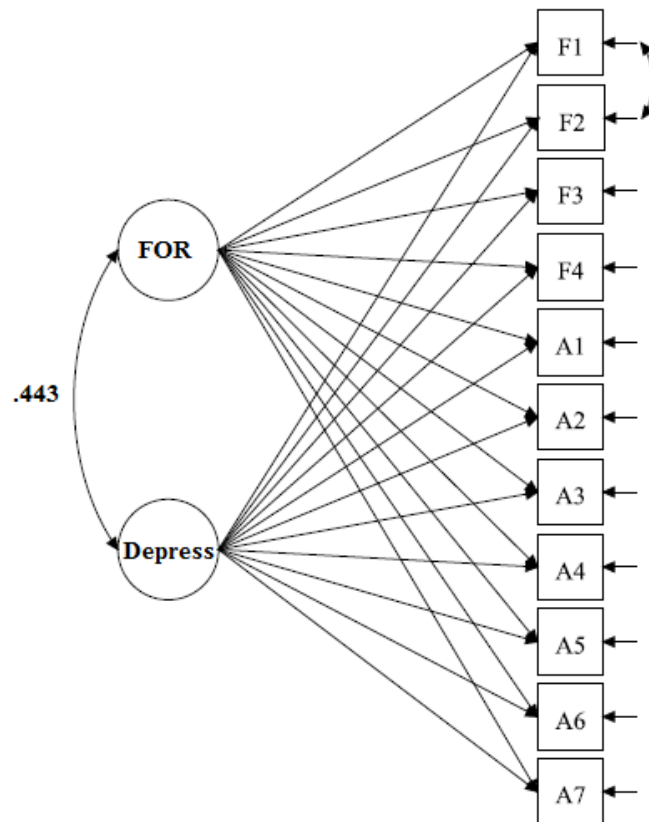


Figure 3.12 ESEM model with fear of recurrence and anhedonic depression.

Correlation shown is significant ( $p < .001$ ). F1-F4: Fear of recurrence items. A1-A7: Anhedonic depression items. FOR: Fear of recurrence factor. Depress: Anhedonic depression factor.

Likewise, with optimism we found that a two-factor structure ( $\chi^2 = 132.19$ ,  $df = 25$ ,  $p < .0001$ , RMSEA = 0.120, CFI = 0.92) fit the data significantly better than a one-factor structure ( $\chi^2 = 360.28$ ,  $df = 34$ ,  $p < .0001$ , RMSEA = 0.179, CFI = 0.75;  $\Delta\chi^2(9) = 228.09$ ,  $p < .0001$ ). Again, however, we found a moderate-to-strong correlation between fear of recurrence and optimism ( $r = -.41$ ,  $p < .001$ ). As we found with the anxious apprehension items, the optimism items, which also included reverse-worded items, better and more clearly fit onto separate factors as part of a three-factor model with fear of recurrence ( $\chi^2 = 9.71$ ,  $df = 17$ ,  $p = .92$ , RMSEA = 0.000, CFI = 1.00;  $\Delta\chi^2(8) = 122.48$ ,  $p < .0001$ ). When specified this way, we found that fear of recurrence was associated with positively-worded optimism items ( $r = -.43$ ,  $p < .001$ ) as well as negatively-worded optimism items ( $r = -.27$ ,  $p < .01$ ; see Figure 3.13).

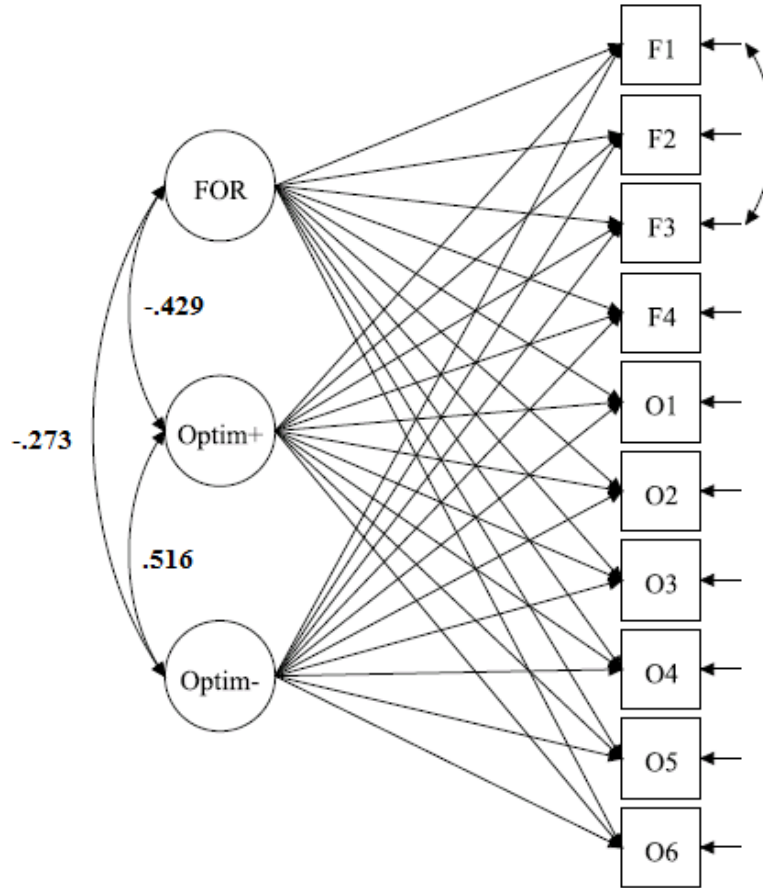


Figure 3.13 ESEM model with fear of recurrence and optimism.

Positively- and negatively worded optimism items each loaded significantly on their own factors. Correlations shown are significant ( $p < .01$ ). F1-F4: Fear of recurrence items. O1-O6: Optimism items. FOR: Fear of recurrence factor. Optim+: Positively-worded optimism factor. Optim-: Negatively-worded optimism factor.

### **3.5 Fear of Recurrence's Relation to Multifaceted Clinical Constructs**

We also used ESEM and bifactor modeling strategies to demonstrate the relationships between fear of recurrence and multifaceted clinical constructs including PTSD, GAD, and general health anxiety.

#### **3.5.1 PTSD**

With regard to PTSD, we initially specified a bifactor model consistent with the current DSM-5 diagnostic criteria involving four symptom clusters (i.e., intrusions, avoidance, etc.); however, this model could not be specified, presumably because of extremely low rates of item endorsement on several PTSD symptom items. Therefore, we utilized ESEM with items treated as categorical variables.

We began with a one-factor model and evaluated improvements in model fit with the addition of more factors. Model fit improved with the addition of factors, and we found that a five-factor ESEM model was interpretable and had excellent fit ( $\chi^2 = 107.74$ ,  $df = 100$ ,  $p = .28$ , RMSEA = .016, CFI = 1.00). The observed factor loadings were not congruent with DSM-5 diagnostic clusters (nor were those of the less well-fitting, four-factor model). Again, this could result from extremely low item endorsement making symptom cluster distinctions difficult to detect, or the fact that PTSD symptoms do not conform to the same structure observed in other populations when examined in the context of a general cancer population. The five-factor ESEM model we observed appeared to reflect the following latent factors: reactivity to cancer reminders (combination of intrusion and avoidance symptoms); hypervigilance/startle; a general cognitive, emotional, arousal changes cluster; a self-blame/taking more risks

cluster (the two least-endorsed, non-reactivity items), and a single-item factor reflecting difficulty recalling aspects of the cancer experience.

We originally predicted that, while fear of recurrence would be related to the general PTSD factor, it would not be related to, or be only weakly related to, intrusion symptoms. The factor structure we observed in our data made this particular hypothesis difficult to test, given the co-loading of avoidance and intrusion symptoms onto a single factor. Nonetheless, with regard to our ESEM PTSD model, we found that fear of recurrence was strongly associated with the reactivity (intrusions and avoidance) factor ( $r = .58, p < .001$ ), as well as the cognitive/emotional/arousal changes factor ( $r = .57, p < .001$ ) and the difficulty remembering the experience factor/item ( $r = .48, p < .001$ ). Fear of recurrence had a moderate-sized, marginally significant association with the hypervigilance/startle factor ( $r = .35, p = .05$ ) and a moderate-sized correlation with the self-blame/risk-taking factor ( $r = .36, p < .01$ ).

To home in further on the research question at hand, we next specified a bifactor model with a general PTSD factor and an intrusion specific factor only, representing what is unique to the intrusion items taking into account what is common to all of the PTSD items. We then evaluated the relationship between fear of recurrence and the specific factor of intrusion symptoms and found that they were weakly associated ( $r = .17, p = .04$ ). It should be noted, however, that the unstandardized effect was not significant ( $p = .07$ ), suggesting that this association is unreliable. The association between fear of recurrence and the general PTSD factor remained robust and significant ( $r = .61, p < .001$ ; see Figure 3.14).

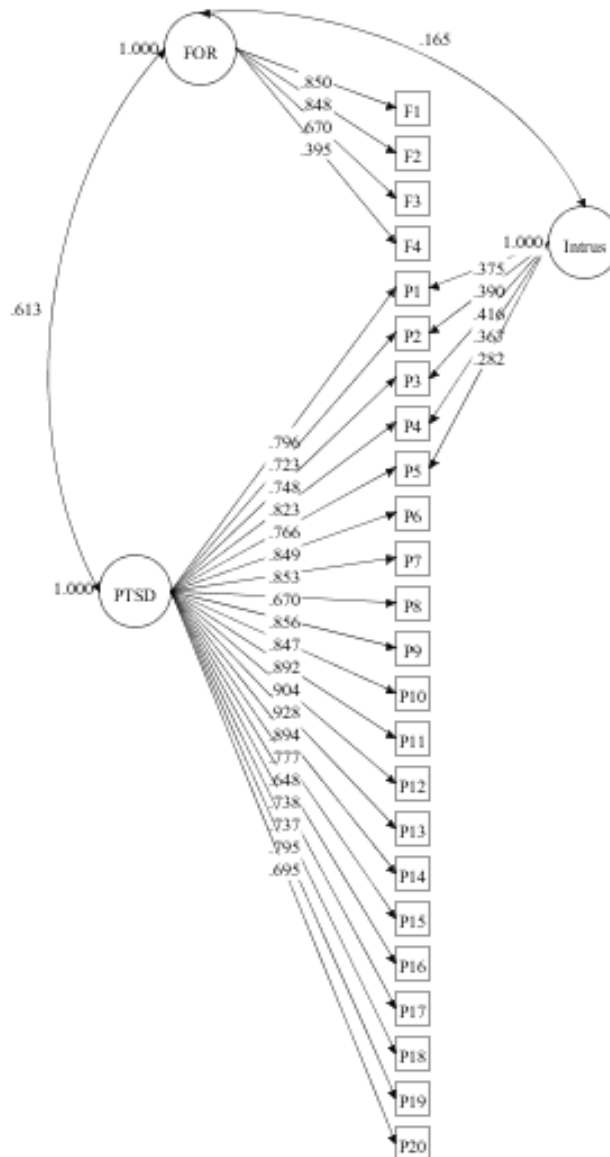


Figure 3.14 PTSD and fear of recurrence bifactor model.

Correlations shown are significant ( $p < .05$ ). F1-F4: Fear of recurrence items. P1-P20: PTSD items. FOR: Fear of recurrence factor. Intrus: Specific factor of intrusions. PTSD: General factor of PTSD.

### 3.5.2 General Health Anxiety

To assess the relationship between fear of recurrence and general health anxiety, we specified a bifactor model with one general factor (health anxiety) and two specific factors: cancer-related health anxiety and non-cancer-related health anxiety. We used bifactor modeling coinciding with the theory of a conceptually broad construct of "health anxiety" and specific facets of "cancer-related health anxiety" and "non-cancer-related health anxiety." Bifactor modeling allowed us to assess the relationship between fear of recurrence and that which is unique to cancer-specific health anxiety after partialling out what is common to cancer-specific and non-cancer-specific health anxiety. It also allowed us to assess the relationship between fear of recurrence and the general health anxiety factor, which includes what is common to cancer-related and non-cancer-related anxiety.

Our prediction was that fear of recurrence would be akin to, and thus highly correlated with, the specific factor of cancer-related health anxiety, whereas it would be more discriminable from the non-cancer-related health anxiety specific factor. We found that this model had suboptimal fit ( $\chi^2 = 534.90$ ,  $df = 103$ ,  $p < .0001$ , RMSEA = .118, CFI = 0.84), so we used the model to test the originally-proposed research question, but then explored additional ways of modeling this set of variables. We found that the latent fear of recurrence factor was most strongly correlated with the cancer-related health anxiety specific factor ( $r = .61$ ,  $p < .001$ ); however, it was also correlated, to a lesser extent, with the health anxiety general factor ( $r = .43$ ,  $p < .001$ ), as well as the non-cancer-related health anxiety specific factor ( $r = .33$ ,  $p < .001$ ).

Again, we ran an inferential test to compare these correlations using bootstrapped standard errors. We found that the fear of recurrence and cancer-related health anxiety correlation was not significantly stronger than the fear of recurrence and non-cancer-related health anxiety correlation, although it was trending in that direction ( $\Delta r = .28$ ,  $SE = .16$ ,  $p = .07$ ). The other contrasts were also non-significant.

In a second analytic approach, we specified an ESEM model that included all the health anxiety items (including those framed around cancer-related illness and those framed around non-cancer related illness), as well as the fear of recurrence items. We found that, moving from a one-factor structure ( $\chi^2 = 1099.62$ ,  $df = 119$ ,  $p < .0001$ , RMSEA = 0.166, CFI = 0.63) to a two-factor structure ( $\chi^2 = 670.54$ ,  $df = 103$ ,  $p < .0001$ , RMSEA = .136, CFI = 0.79) led cancer-related health anxiety items to load on the same factor as fear of recurrence items while non-cancer-related health anxiety items loaded onto the second factor (see Figure 3.15).

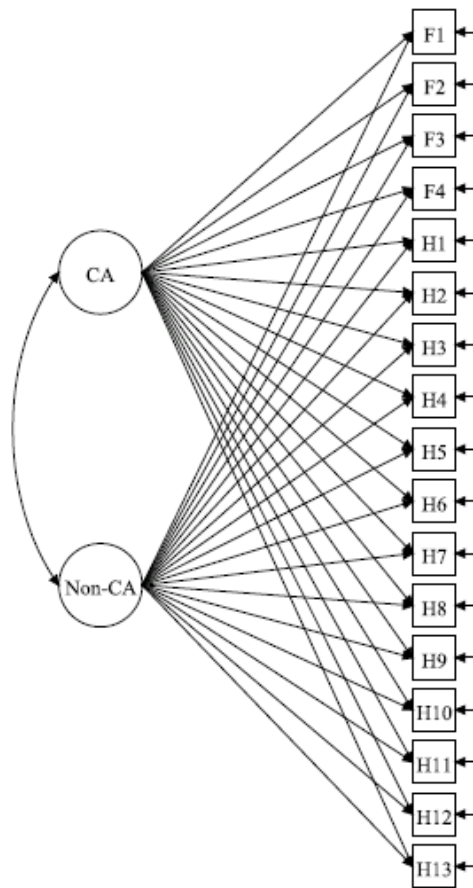


Figure 3.15 ESEM model of fear of recurrence and health anxiety.

Moving from a one-factor model to this two-factor ESEM model, fear of recurrence items loaded together with cancer-related health anxiety items onto one factor, and non-cancer-related health anxiety items loaded on a second factor. F1-F4: Fear of recurrence items. H1-H13: Health anxiety items (some framed around cancer). CA: Cancer-related concerns factor (with high loadings for fear of recurrence and cancer-related health anxiety items). Non-CA: Non-cancer-related health concerns factor (with high loadings for non-cancer-related health anxiety items).

### 3.5.3 GAD

We used bifactor modeling again with GAD, as it allowed us to evaluate fear of recurrence's relationship to the conceptually broad, general factor of GAD as well as the unique aspects of the conceptually narrower facets of GAD (i.e., diffuse worry, excessive worry).

We predicted that fear of recurrence would be related to GAD overall, but not the specific facet of GAD that involves worry about many topics (i.e., diffuse worry). We specified a bifactor model with a general GAD factor as well as a specific factor of diffuse worry. We then evaluated the relationship between fear of recurrence and the general factor of GAD, as well as fear of recurrence and the specific factor of GAD relating to diffuse worry. We found that fear of recurrence was strongly associated with the general GAD factor ( $r = .59, p < .001$ ), but it was also, to a lesser extent, associated with the specific factor of GAD relating to diffuse worry ( $r = .21, p < .01$ ; see Figure 3.16). We found that this difference in correlations was statistically significant ( $\Delta r = .37, SE = .10, p < .001$ ).

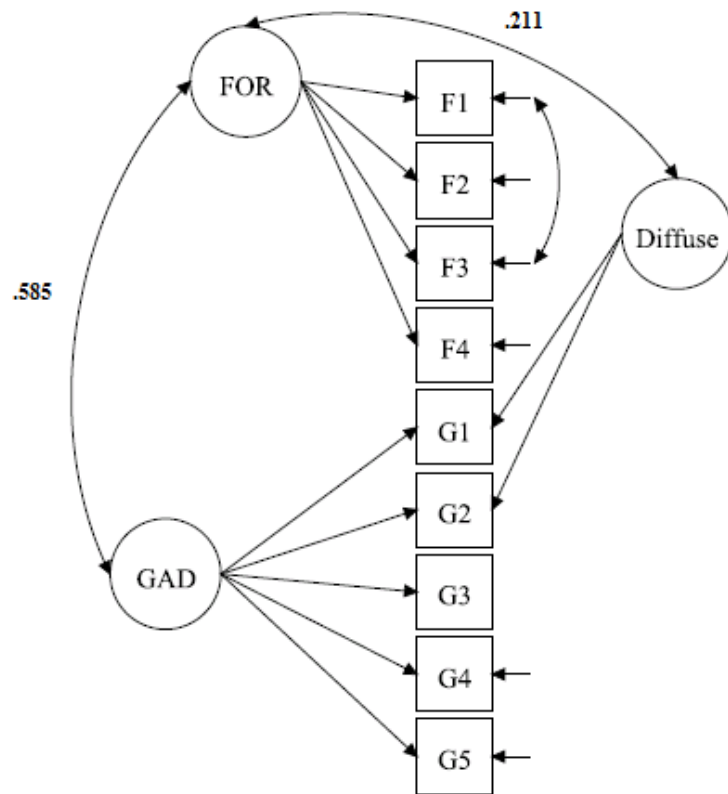


Figure 3.16 GAD and fear of recurrence bifactor model.

Correlations shown are significant ( $p < .05$ ). F1-F4: Fear of recurrence items. G1-G5: GAD items. FOR: Fear of recurrence factor. Diffuse: Specific factor of diffuse worry. GAD: General factor of GAD.

### **3.6 Assessing Fear of Recurrence's Unique Predictive Power**

Finally, we tested our hypothesis that fear of recurrence has predictive power over and above other theoretically-related constructs. To do so, we modeled a bifactor structure that included, as its specific factors, fear of recurrence, anxious apprehension, anxious arousal, and uncertainty intolerance. The general factor—what each of these specific factors has in common—might be called something like “anxiety.” We then tested our hypothesis that the specific factor of fear of recurrence—which separates out the unique aspects of fear of recurrence from what all of these constructs have in common—would remain a significant predictor of survivors' self-reported behavioral outcomes (e.g., health care utilization, self-examination, etc.; see Figure 3.17). We found support for the unique predictive power of fear of recurrence. In our bifactor model, the specific factor of fear of recurrence remained a significant predictor of each of the originally significant behavioral outcomes, with the exception of disengagement (see Table 3.4).

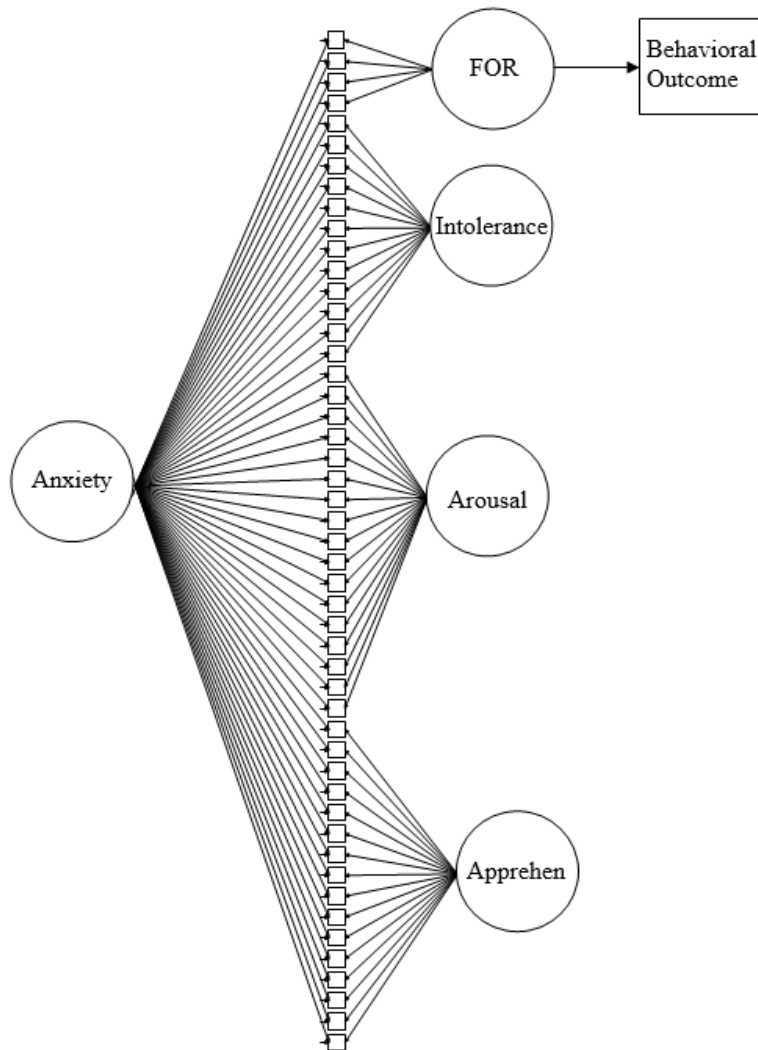


Figure 3.17 Anxiety bifactor model.

This model was specified for each behavioral outcome. Each behavioral outcome (e.g., self-examination) was regressed on the specific factor of fear of recurrence, which includes that which is unique to fear of recurrence over and above that which is common to fear of recurrence, anxious apprehension, anxious arousal, and uncertainty intolerance. We also ran a more stringent model with the general factor and other specific factors included as covariates.

Table 3.4 Specific Factor of Fear of Recurrence from Bifactor Model as a Predictor of Behavioral Outcomes

Behavioral Outcome	<i>b</i>	95% CI	<i>OR</i>	95% CI	<i>SE</i>	<i>p</i> -value
MH counseling <sup>a</sup>	0.40	0.13 - 0.68	1.50	1.14 - 1.97	0.17	.02
MH medication <sup>a</sup>	0.52	0.25 - 0.78	1.67	1.28 - 2.18	0.16	<.01
MH recommendation <sup>a</sup>	0.69	0.37 - 1.01	1.99	1.45 - 2.75	0.20	<.001
Recent oncology visit <sup>a</sup>	0.45	0.19 - 0.72	1.57	1.21 - 2.05	0.16	<.01
Annual oncology visits <sup>b</sup>	3.18	1.00 - 5.35	--	--	1.32	.02
Recent oncology call <sup>a</sup>	0.62	0.31 - 0.93	1.86	1.36 - 2.53	0.19	<.01
Annual oncology calls <sup>b</sup>	1.06	0.29 - 1.82	--	--	0.47	.02
Flourishing	-0.17	-0.30 - -0.03	--	--	0.08	.04
Disengagement <sup>b</sup>	0.28	0.03 - 0.54	--	--	0.15	.07
Self-examination	0.30	0.14 - 0.47	--	--	0.10	<.01
Functional impairment	0.39	0.29 - 0.50	--	--	0.06	<.001

<sup>a</sup>These outcomes are dichotomous; as such, odds ratios are also provided for these outcomes.

<sup>b</sup>These outcomes are count variables.

To further test the limits of the predictive power of fear of recurrence, we also re-ran the aforementioned anxiety bifactor model, this time including the other specific factors (anxious apprehension, uncertainty intolerance, and anxious arousal), as well as the general anxiety factor, as covariates in the prediction of behavioral outcomes.

As shown in Table 3.5, we found that, when controlling for all these factors, fear of recurrence remained a significant predictor of the occurrence (yes/no) of oncology visits and calls, physical self-examination, and functional impairment. Due to modeling specification limits for count outcomes, we included only the general anxiety factor as a covariate with fear of recurrence in the prediction of number of oncology visits and calls in the past year. We found that specific fear of recurrence

factor remained a significant predictor of oncology visits and calls when controlling for the general factor (that which is common to fear of recurrence, anxious apprehension, anxious arousal, and uncertainty intolerance). When including covariates, fear of recurrence was no longer a significant predictor of mental health treatment outcomes or flourishing. For these outcomes, we found that the general anxiety factor was a significant predictor. Anxious arousal emerged also as a significant, unique predictor of mental health medication, mental health recommendations, and flourishing.

Table 3.5 Bifactor Multiple Regression Results.

Outcome/Predictors	<i>b</i>	95% CI	<i>SE</i>	<i>OR</i>	95% CI	<i>p</i> -value
<b>MH counseling<sup>a</sup></b>						
General anxiety	0.31	0.11 - 0.51	0.12	1.37	1.12 - 1.67	.01
Fear of recurrence	0.14	-0.09 - 0.37	0.14	1.15	0.91 - 1.45	.32
Anxious apprehension	-0.03	-0.24 - 0.19	0.13	0.97	0.79 - 1.21	.83
Uncertainty intolerance	0.54	0.00 - 1.08	0.33	1.71	1.00 - 2.94	.10
Anxious arousal	0.24	-0.08 - 0.57	0.20	1.27	0.92 - 1.77	.22
<b>MH medication<sup>a</sup></b>						
General anxiety	0.60	0.41 - 0.79	0.12	1.82	1.51 - 2.20	<.001
Fear of recurrence	0.04	-0.15 - 0.23	0.12	1.04	0.86 - 1.26	.73
Anxious apprehension	-0.04	-0.22 - 0.14	0.11	0.96	0.80 - 1.15	.74
Uncertainty intolerance	0.30	-0.17 - 0.77	0.28	1.35	0.84 - 2.16	.29
Anxious arousal	0.53	0.23 - 0.84	0.19	1.70	1.26 - 2.32	<.01
<b>MH recommendation<sup>a</sup></b>						
General anxiety	0.57	0.35 - 0.79	0.13	1.77	1.42 - 2.20	<.001
Fear of recurrence	0.24	-0.03 - 0.51	0.16	1.27	0.97 - 1.67	.15
Anxious apprehension	-0.12	-0.32 - 0.08	0.12	0.89	0.73 - 1.08	.31
Uncertainty intolerance	0.29	-0.23 - 0.80	0.31	1.33	0.79 - 2.23	.36
Anxious arousal	0.57	0.24 - 0.91	0.20	1.77	1.27 - 2.48	<.01
<b>Flourishing</b>						
General anxiety	-0.72	--	0.11	--	--	<.001
Fear of recurrence	-0.05	--	0.07	--	--	.47
Anxious apprehension	0.03	--	0.15	--	--	.82
Uncertainty intolerance	0.56	--	1.21	--	--	.65
Anxious arousal	-0.47	--	0.15	--	--	<.01
<b>Self-examination</b>						
General anxiety	0.20	--	0.13	--	--	.13
Fear of recurrence	0.30	--	0.10	--	--	<.01
Anxious apprehension	0.02	--	0.22	--	--	.92
Uncertainty intolerance	-0.70	--	1.43	--	--	.63
Anxious arousal	0.02	--	0.22	--	--	.92
<b>Functional impairment</b>						
General anxiety	0.67	--	0.09	--	--	<.001
Fear of recurrence	0.26	--	0.05	--	--	<.001
Anxious apprehension	-0.25	--	0.12	--	--	.04
Uncertainty intolerance	0.64	--	0.69	--	--	.35
Anxious arousal	0.40	--	0.11	--	--	<.001

<sup>a</sup>These outcomes are dichotomous; as such, odds ratios are also provided for these outcomes.

<sup>b</sup>These outcomes are count variables.

Table 3.5 Continued

Outcome/predictors	<i>b</i>	95% CI	<i>SE</i>	<i>OR</i>	95% CI	<i>p</i> -value
Recent oncology visit <sup>a</sup>						
General anxiety	0.16	-0.02 - 0.34	0.11	1.17	0.98 - 1.40	.13
Fear of recurrence	0.31	0.08 - 0.53	0.14	1.36	1.08 - 1.70	.03
Anxious apprehension	0.05	-0.14 - 0.24	0.12	1.05	0.87 - 1.27	.66
Uncertainty intolerance	0.42	-0.09 - 0.94	0.31	1.52	0.91 - 2.56	.17
Anxious arousal	-0.12	-0.43 - 0.19	0.19	0.89	0.65 - 1.21	.52
Annual oncology visits <sup>b</sup>						
General anxiety	0.19	-0.02 - 0.40	0.13	--	--	.13
Fear of recurrence	3.41	1.04 - 5.78	1.44	--	--	.02
Recent oncology call <sup>a</sup>						
General anxiety	0.28	0.07 - 0.49	0.13	1.32	1.07 - 1.63	.03
Fear of recurrence	0.40	0.15 - 0.64	0.15	1.49	1.16 - 1.90	<.01
Anxious apprehension	0.28	0.03 - 0.53	0.15	1.32	1.03 - 1.70	.07
Uncertainty intolerance	0.36	-0.28 - 1.00	0.39	1.43	0.76 - 2.72	.36
Anxious arousal	0.12	-0.26 - 0.49	0.23	1.12	0.77 - 1.63	.61
Annual oncology calls <sup>b</sup>						
General anxiety	0.54	0.28 - 0.80	0.16	--	--	<.01
Fear of recurrence	0.87	0.05- 1.68	0.50	--	--	.08

<sup>a</sup>These outcomes are dichotomous; as such, odds ratios are also provided for these outcomes.

<sup>b</sup>These outcomes are count variables.

## Chapter 4

### DISCUSSION

We proposed and evaluated a cognitive-emotional theory of fear of recurrence involving future-oriented worry, risk-based cognitive discrepancy (e.g., an overestimation of risk relative to actual risk), and fear-related emotions based on previous research and an untested cognitive-behavioral formulation of fear of recurrence (Lee-Jones et al., 1997). After systematically culling items because of wording or context redundancy, we found that theory-consistent items were part of a well-fitting model of fear of recurrence. The latent fear of recurrence factor then was used to predict relevant behavioral outcomes including cancer-related health care utilization, mental health treatment, physical self-examination, goal-striving, and functional impairment.

We went on to evaluate whether fear of recurrence is a unique construct, distinguishable from other, theoretically-similar constructs, and found evidence for the discriminant validity of the theory-consistent fear of recurrence items. Namely, fear of recurrence consistently emerged as its own factor when modeled with well-established measures of anxious apprehension, anxious arousal, uncertainty intolerance, depression, and optimism. Furthermore, it differed in key respects from other clinical constructs including PTSD, general health anxiety, and GAD. Perhaps of greatest interest, fear of recurrence remained a significant predictor of several relevant behavioral outcomes when accounting for the effects of other similar anxiety

constructs. In the following sections, we discuss each of these findings in greater detail.

#### **4.1 Fear of Recurrence as a Predictor of Behavioral Outcomes**

We found that the latent factor of fear of recurrence was a significant predictor of mental health counseling ( $OR = 1.77$ ), use of psychotropic medications ( $OR = 2.16$ ), and being advised to seek mental health treatment since diagnosis ( $OR = 2.94$ ); the occurrence of phone calls ( $OR = 2.26$ ) and visits ( $OR = 1.84$ ) to oncology providers' offices within the past three months; the number of phone calls ( $RR = 3.13$ ) and visits ( $RR = 13.87$ ) to oncology providers in the past year; flourishing (i.e., "psychological prosperity;"  $b = -0.45$ ); disengagement from life activities ( $RR = 1.67$ ); frequency of physical self-examination for signs and symptoms of cancer ( $b = 0.39$ ); and functional impairment ( $b = 0.63$ ). These findings suggest that items deriving directly from a cognitive-emotional model of fear of recurrence can cohere as a factor and predict meaningful behavioral outcomes relevant to breast cancer survivors.

Of note, fear of recurrence did not predict encounters with primary care physicians nor engagement in life activities. The observed distinction between oncology and primary care encounters suggests that fear of recurrence is related to cancer-specific health care utilization, but not health care utilization overall. Although it is not what we had initially predicted, this finding is consistent with the finding that the latent fear of recurrence factor was strongly correlated with, and loaded with, cancer-related health anxiety items whereas it was moderately correlated with non-cancer-related health anxiety items. It is also consistent with the fact that cancer

patients are advised to see their oncologist for cancer-related follow-up concerns, not their primary care provider. Thus, although we expected to find that fear of recurrence was associated with increased health care utilization overall, its effect appears to be more specific to oncology healthcare utilization alone.

We also found that fear of recurrence failed to predict decreased engagement in life activities (e.g., developing new relationships, pursuing an educational goal), although it was associated with other measures of forward action/goal striving including greater disengagement from life activities (e.g., pulling away from relationships, leaving a position, cancelling plans or purchases) and flourishing (e.g., having meaning and purpose in life, being engaged and interested in daily activities). To further examine this discrepancy, we specified a goal-striving factor comprised of the engagement, disengagement, and flourishing composite items. Interestingly, the loading of engagement on the goal-striving factor was only approaching significance ( $\lambda = 0.20$ ,  $SE = 0.11$ ,  $p = .07$ ). Nonetheless, fear of recurrence significantly predicted the overall goal-striving factor ( $b = -0.46$ ,  $SE = 0.09$ ,  $p < .001$ ).

The discrepancy between the engagement variable and the disengagement variable could suggest that engagement in life activities overall is spared by fear of recurrence (i.e., engagement in life activities continues regardless of high levels of fear of recurrence). Alternatively this non-significant finding could reflect insensitivity of the engagement measure, as we used an unpublished checklist of items we felt reflected forward action developed specifically for this project, but which could be improved in future research (e.g., use of more varied items, use of a Likert-type scale

as opposed to a yes or no response option). For example, it may be the case that the engagement checklist was more focused on extraverted and social activities than other forms of engagement. In follow-up analyses, we found that existing scales that measure fear of recurrence (i.e., the FCRI and CARS) also did not predict engagement.

Our finding that fear of recurrence was unrelated to positive health changes was also noteworthy. We did not make specific predictions about this variable as there was unclear evidence to suggest whether fear of recurrence might be motivating, leading to positive changes, or debilitating and preventing positive changes. Although we considered both non-linear as well as linear relationships with fear of recurrence, and tested for possible moderated effects, we found that there was no discernible association between these variables. In light of these null findings, we considered the possibility that threat perception alone may be a better predictor positive changes; however, participants' perceived risk of recurrence was also unrelated to positive changes.

The lack of a significant association between fear of recurrence and positive changes fits with an inconsistent existing literature on behavioral changes after cancer (Park & Gaffey, 2007). Indeed, it appears that the relationship between cancer-related distress and positive behavioral change is complex and potentially dependent on a variety of integrated factors. Social-cognitive processing theory is one framework for viewing adjustment to cancer (Lepore, 2001; Lepore & Revenson, 2007). According to this theory, positive benefits from social support may stem from disclosure of

stressful thoughts and emotions, which in turn may facilitate emotional habituation and cognitive processing and successful adjustment to the cancer experience. Thus, fear alone may not be enough, and positive behavioral change may be more likely once the distressing event is successfully processed. Certainly, future research is needed to better understand which variables, or combinations of variables, predict positive changes such as behavioral modifications that might reduce one's risk of recurrence.

We did, however, find evidence for a non-linear relationship between fear of recurrence and health care utilization (i.e., number of calls to oncology providers in the past year). These findings suggest that the effect of fear of recurrence on oncology office calls may not be equal at all levels of fear of recurrence and that different patterns may emerge across the continuum of possible values. That said, we did not find evidence of the same relationship when we examined fear of recurrence's relationship with this health care outcome using the FCRI and CARS. This discrepancy highlights the need for additional research on the potentially complex relationship between fear of recurrence and health care outcomes and how best to measure such nuance. One hope was to identify whether there is some point at which fear of recurrence becomes problematic. This finding provides some indication that there may be a point when above-average levels of fear of recurrence lead to disproportionately high rates of outcomes. However, that we were unable to find evidence of this trend using existing measures of fear of recurrence precludes identification of a particular cut point.

We also predicted that the variables of acceptance and avoidance would moderate the relationships between fear of recurrence and negative behavioral outcomes. We predicted that acceptance would attenuate the negative effects of fear of recurrence on functional impairment and goal-striving. We found that the *fear of recurrence x acceptance* interaction was a significant predictor of functional impairment. For those low in acceptance, fear of recurrence continued to be associated with increased functional impairment, whereas, for those high in acceptance, there was no longer any association between these variables. This pattern of results suggests that an acceptance-based willingness to experience unwanted thoughts and emotions and move in valued directions in spite of negative psychological experiences can serve as a protective buffer against the negative effects of fear of recurrence on important areas of functioning (e.g., social, work, relationships). This finding has potential implications for intervention, such that, if individuals can be taught to take a more acceptance-based stance following cancer, doing so may mitigate the disruptive effects of fear of recurrence, at least on functional outcomes. We did not, however, find that acceptance moderated the relationship between fear of recurrence and goal-striving (disengagement, flourishing), suggesting that the protective effects of acceptance may not generalize to all behavioral outcomes.

With regard to our second potential moderator, avoidance, we found that this variable did not moderate the relationships between fear of recurrence and any of the physical self-examination or health care utilization outcomes as we had predicted.

One potential limitation worth noting is that, in the present study, avoidance was measured with a single item. Additionally, it may be the case that few of the most avoidant breast cancer survivors opted to participate in this study, making it difficult to detect a moderation effect. This issue is discussed further in the limitations section below. Future research may benefit from a more intensive evaluation of avoidance or from varied conceptualizations of avoidance (e.g., avoidance of internal versus external sources of anxiety) to further explore any potentially moderating role of this variable.

Finally, we found that three relationships were also moderated by time since diagnosis: number of oncology visits in the past year, mental health counseling since diagnosis, and frequency of self-examination. We found that the relationship between fear of recurrence and annual oncology visits was significant at one year since diagnosis but not at four and seven years since diagnosis, suggesting that the effect of fear of recurrence on increased oncology visits is driven by those individuals who were more recently diagnosed with breast cancer. We found that the relationship between fear of recurrence and mental health counseling, as well as the relationship between fear of recurrence and self-examination, was significant at four and seven years since diagnosis but not at one year since diagnosis, suggesting the effect between fear of recurrence on these outcomes is not apparent among those recently diagnosed with breast cancer, but later in survivorship.

Taken together, these findings suggest that fear of recurrence's effect on oncology visits, mental health counseling, and of self-examination may depend on

how much time has passed since diagnosis. Early in survivorship, fear of recurrence may lead one to have more frequent visits to one's oncologist; however, this effect appears to fade over time. By contrast, as time passes, the relationship between fear of recurrence and self-examination and mental health counseling becomes stronger. One possibility is that there may be more variability in counseling and self-examination soon after diagnosis and treatment, and the effects of fear of recurrence on these outcomes may become more apparent later on. It makes sense that those still experiencing fear of recurrence long after diagnosis might be particularly motivated to seek out counseling if their distress has not subsided naturally.

#### **4.2 Fear of Recurrence's Relation to Other Constructs**

A second aim of this study was to assess the relationship between fear of recurrence and other theoretically-related constructs. We explored the relations between fear of recurrence and GAD, PTSD, general health anxiety, anxious apprehension, uncertainty intolerance, and anxious arousal. With regard to the clinical diagnosis variables, our aim was to establish fear of recurrence's place among these more well-studied constructs and identify in which respects it is similar and different.

We predicted that fear of recurrence would overlap with many features/symptoms of PTSD, but less so with the facet of PTSD that involves retrospective intrusions. We had difficulty replicating the factor structure inherent in the DSM-5 conceptualization of PTSD in our sample. As noted earlier, this could be due to the fact that there was a low base rate of PTSD symptoms overall in our non-clinical sample of early-stage breast cancer survivors. Thus, our PTSD results are best

viewed cautiously. That said, when we modeled the specific factor of intrusion symptoms we found that it was relatively weakly and not reliably associated with fear of recurrence ( $r = .17$ ), whereas the general PTSD factor (that which all the specific factors have in common) was significantly related ( $r = .61$ ). This was consistent with our hypothesis that fear of recurrence would have conceptual overlap with PTSD, but that fear of recurrence would be less related to that aspect of PTSD that involves re-experiencing of a past event, as we predicted that fear of recurrence is more worry- and future-oriented. Notably, the strength of the relationship between fear of recurrence and the general factor of PTSD was greater than predicted. Whereas we expected a correlation in the small-to-moderate range, the observed correlation was in the strong range.

As predicted, we also found that the latent fear of recurrence factor was strongly correlated with cancer-related health anxiety ( $r = .61$ ). Although not reaching statistical significance, fear of recurrence's link with cancer-related health anxiety was marginally stronger than the link with non-cancer-related health anxiety ( $r = .33$ ;  $\Delta r = .28$ ,  $p = .07$ ). This result suggests that fear of recurrence is not the same as general health anxiety, although it does share some conceptual overlap. Furthermore, that cancer-related health anxiety items and fear of recurrence items loaded on the same factor lends support to the possibility that fear of recurrence is akin to cancer-specific health anxiety. Again, however, we found that correlations between fear of recurrence and these constructs were stronger than expected. While we predicted that fear of recurrence would be associated with cancer-related health anxiety reflecting a

moderate-sized correlation, the effect size was large. Also, the relationship between fear of recurrence and non-cancer-related health anxiety was moderate in strength.

We predicted that fear of recurrence would also be largely overlapping with GAD symptoms but that a distinguishing feature would be fear of recurrence's exclusive focus on cancer worry, with little diffusion of worry to other topics. We found mixed support for this prediction, as fear of recurrence was strongly associated with the general GAD factor ( $r = .59$ ), but it was also associated with the specific factor of GAD relating to diffuse worry in the small-to-moderate range ( $r = .21$ ). This suggests those high in fear of recurrence may in fact have a propensity for diffuse worry that may not be concentrated solely on the possibility of cancer recurrence. This finding would also fit with the perspective that those who are most at risk for fear of recurrence are those who already have a trait tendency to worry, whereas those not typically worrisome by nature may be less prone to fear of recurrence. This interpretation is consistent with the relatively strong correlations we found between fear of recurrence and anxious apprehension, as described further below

In addition to these clinical constructs, we also evaluated fear of recurrence's relation to the broader, anxiety-based, individual difference constructs of anxious apprehension, uncertainty intolerance, and anxious arousal. We proposed that fear of recurrence would demonstrate a moderate link to each of these constructs (especially anxious apprehension and uncertainty intolerance); however, we also expected fear of recurrence to emerge as an independent construct in factor models. We found evidence in support of this prediction, as two-factor models of fear of recurrence and

other constructs' items consistently fit the data better than one-factor models. This suggests that fear of recurrence is discriminable from other constructs on the most basic level, and further evidence for the distinctiveness of fear of recurrence comes from the unique predictive power analyses described in greater detail below.

While fear of recurrence consistently emerged as its own unique factor when examined with other anxiety construct items, inter-factor correlations (e.g., fear of recurrence with anxious apprehension) were higher than expected (e.g., moderate-to-strong range), particularly given that we used ESEM, which permitted non-zero cross-factor item loadings and which would therefore be expected to decrease the effect size of such correlations. Thus, although fear of recurrence is distinguishable from other constructs, it is also overlapping to a high degree, especially with anxious apprehension ( $r = .41$  with positively-worded items) and uncertainty intolerance ( $r = .45$ ). These findings suggest that fear of recurrence is similar to anxiety, overall, and especially similar to more cognitive (e.g., worry) aspects of anxiety, as opposed to physiological arousal ( $r = .30$ ).

We also examined fear of recurrence's relation to two variables that we anticipated would be even more discriminable. Consistent with our hypotheses, we found that fear of recurrence emerged as a unique factor when modeled with anhedonic depression and optimism items. While we predicted that fear of recurrence would be weakly associated with these variables, we found that the strength of the associations were also in the moderate-to-strong range ( $r = .44$  for anhedonic depression and  $r = -.43$  for positively-worded optimism). This finding was surprising,

as we hypothesized that depression and optimism were more dissimilar to fear of recurrence than anxiety constructs. These correlations were comparable to those between fear of recurrence and anxious apprehension and uncertainty intolerance, suggesting that fear of recurrence is not characterized by "fear" or worry alone, but also very much related to lack of positive affect and pessimism. That fear of recurrence was correlated more strongly than anticipated with virtually all of the variables assessed in this study also suggests that factors such as response styles (i.e., person-based patterns in responding to survey items such as acquiescence) may have contributed to high inter-scale correlations (e.g., Van Vaerenbergh & Thomas, 2012). This is a limitation of self-report data discussed further below. Although fear of recurrence's high correlations with these constructs do not provide as much evidence of discriminant validity as we would have expected, again, the unique predictive power of fear of recurrence helps to further demonstrate its independence.

### **4.3 Fear of Recurrence's Unique Predictive Power**

Of central interest, we found that, when partialling out what is common to fear of recurrence, anxious apprehension, uncertainty intolerance, and anxious arousal, the specific factor of fear of recurrence (that which is unique to fear of recurrence) remained a significant predictor of relevant behavioral outcomes. This finding lends strong support of the construct's unique predictive power. We predicted that fear of recurrence would remain a significant predictor, particularly of the behavioral outcomes of health care utilization, self-examination, and goal-striving, although we evaluated all of the behavioral outcomes in turn. Even when including the effects of

anxious apprehension, uncertainty intolerance, and anxious, the specific factor of fear of recurrence remained a significant predictor of oncology office visits ( $OR = 1.36$ ,  $RR = 30.27$ ) and calls ( $OR = 1.49$ ,  $RR = 2.39$ ), physical self-examination ( $b = 0.30$ ), and functional impairment ( $b = 0.26$ ). Thus, fear of recurrence was a particularly robust predictor of these outcomes above and beyond related anxiety constructs.

Outcomes that were no longer significant after controlling for the specific effects of anxious apprehension, uncertainty intolerance, and anxious arousal included goal-striving variables (i.e., disengagement and flourishing) and mental health treatment outcomes (i.e., counseling, medication, and treatment recommendation). For these outcomes, we found that the general factor, which took into account what fear of recurrence, anxious arousal, anxious apprehension, and uncertainty intolerance have in common, was a significant predictor. This finding suggests that mental health treatment outcomes are not uniquely predicted by fear of recurrence but predicted by general anxiety, a finding that makes sense logically since we inquired about mental health treatment broadly. Another significant predictor of these mental health outcomes (with the exception of mental health counseling) was anxious arousal, suggesting that this specific anxiety construct is a robust predictor of mental health outcomes and that physiological experiences of anxiety (e.g., panic-like symptoms) may be especially motivating symptoms for seeking out mental health treatment.

We observed the same pattern of results with the goal-striving variables, such that the general factor of anxiety predicted these outcomes, whereas the unique fear of recurrence factor did not. Again, this suggests that anxiety symptoms overall predict

disengagement from life activities and decreased psychological prosperity, and that fear of recurrence does not predict such outcomes over and above the effects of anxiety in general. Taken together, the above findings suggest that fear of recurrence is a unique construct with predictive power, particularly for cancer-specific outcomes including oncology health care utilization, physical self-examination for signs and symptoms of cancer, and functional impairment.

#### **4.4 Clinical Implications**

Our results pose some possible clinical implications for those working with cancer survivors. For survivors who are high in fear of recurrence, providers may anticipate that outcomes such as increased health care utilization and functional impairment are more likely to occur. Certainly there are many possible means of intervening with these important individuals, and ongoing work focused specifically on treatment with cancer survivors is warranted to further explore the most effective interventions for fear of recurrence-related distress. A few comments are provided based on the findings from this study and within the context of the existing literature on psychosocial interventions for cancer survivors.

As discussed earlier, the transition from cancer patient to cancer survivor can be a difficult one, with a sudden shift to an absence of medical attention (Stanton et al., 2005). Thus, one potential area of intervention may be education, such as reviewing medical information again, at the end of treatment during the transition to survivorship, particularly with the purpose of clarification of health care information such as risk of recurrence. Our data suggest that providers may wish to consider the

potential for survivors to overestimate their risk of recurrence. In our sample, the average discrepancy between actual and perceived risk was a positive value ( $M = 8.61$ ,  $SD = 27.25$ ;  $t(283) = 5.32$ ,  $p < .001$ ), indicative of an overall tendency to overestimate risk of recurrence. Further, 11% of the sample reported that their perceived risk of having breast cancer again within 10 years from diagnosis was above 60%, when, in fact, our objective estimates of risk calculated from clinical information suggested that no participant in our study had a 10-year recurrence risk greater than 60%. Twenty-seven percent of the sample perceived their 10-year risk to be 50% or above when less than 2% of the sample had such risk. Three percent of our sample even perceived a risk of 90% or greater. Given that patients are presented with a great deal of information, much of which is technical medical information, and considering the inherently stressful context in which such information is delivered, there are vast opportunities for miscommunication of risk and other prognostic information. While minor distortions of one's risk may not be in and of themselves problematic, large discrepancies may lead to unnecessary distress. As one example, in a large, longitudinal study of women newly diagnosed with breast cancer, researchers found that most patient who received contralateral prophylactic mastectomy had no significant genetic or familial risk factors for contralateral disease, whereas greater worry about the risk of recurrence drove decisions to receive this procedure even though it has not been shown to reduce the risk of recurrence (Hawley et al., 2014). Given the weight that recurrence distress can carry with such significant treatment decisions, clear communication about the patient's health status and prognosis during

the transition from patient to survivor may serve as a helpful primary intervention to avoid unnecessary escalation of distress later on.

On a secondary level, once survivors are already distressed and experiencing fear of recurrence, it may be worthwhile to explore survivors' perception of risk, and, when discrepant with clinical prognostic information, provide education and assist survivors to alter any misinformation. It is of course possible that survivors may perceive greater risk in spite of clear presentation of clinical information, as anxiety is, by some characterizations, borne from a pathological fear structure involving erroneous risk information. Although not one of the central measures in this study, we asked participants how they thought their degree of risk of recurrence compared to "other breast cancer survivors like [them] (e.g., same age, stage, treatment, etc.)." We found that 7.3% of breast cancer survivors in our sample perceived their risk of recurrence as higher than that of other breast cancer survivors like them. Perceived relative risk was also associated with increased fear of recurrence ( $r = .50, p < .001$ ). Providers may choose to address such situations as with other anxiety-related conditions, including cognitive strategies (e.g., recognizing catastrophic thinking, playing out potential "worst case scenarios," etc.). However, it may also be worth exploring whether there are realistic reasons that such survivors indicated that they were at higher risk (e.g., awareness that they are not following health care recommendations), which could also lead to helpful cognitive or behavioral interventions.

A number of researchers have been examining interventions relevant for survivors with fear of recurrence. Most research has focused on interventions delivered during diagnosis and treatment, with less research on interventions for survivors post-treatment (see Stanton, 2006 for an overview); however, there is evidence that even interventions delivered during treatment may lead to long-term positive outcomes during survivorship. For example, in one study, an 8-week educational intervention for women with early-stage breast cancer led to improved quality of life maintained three years later (Helgeson et al., 2001, cited in Stanton, 2009).

Existing psychosocial interventions for breast cancer patients and survivors incorporate a diverse array of approaches including education, support, coping skill development, cognitive restructuring, and relaxation training (Stanton, 2006). For example, in one randomized-controlled trial, researchers found that a four-week, cognitive-behavioral telephone-based uncertainty management intervention delivered to breast cancer survivors five to nine years post-treatment led to improvements in cognitive reframing, cancer knowledge, patient-health care provider communication, and coping skills relative to care as usual (Mishel et al., 2005). In another randomized controlled trial, researchers found that a 6-week Mindfulness-Based Stress Reduction (MBSR) program administered to early stage breast cancer survivors within 18 months of treatment completion led to significantly lower levels of depression, anxiety, and fear of recurrence and higher levels of energy and physical functioning, relative to care as usual (Lengacher et al. 2009). The Adjustment to Fear Threat or Expectation

of Recurrence (AFTER) intervention (Humphris & Ozakinci, 2008) is another promising intervention for cancer survivors. It is a six-session, patient-centered approach that involves assessment, optional involvement of caregivers, expression of fears of recurrence, review of patient beliefs about sensations and their interpretation as recurrence, examination of function of checking behavior, and relaxation practice. This intervention targets many of the negative outcomes addressed in this study, especially physical self-examination and worry cognitions, and it was developed with a population of head and neck cancer survivors in mind, a group with particularly high recurrence rates and thus, oftentimes, high fear of recurrence rates as well. These interventions appear to be promising avenues for working with survivors struggling with concerns about recurrence risk, and we look forward to future research in this relatively new area.

Interestingly, and to our surprise, 44.8% of the sample indicated that they perceived themselves at lower risk than other breast cancer survivors like them. Although we expected that the vast majority of survivors would indicate that they are at the same risk level as others with their same clinical and demographic features (47.3% did so), it appears that about just as many placed themselves in a lower risk category. Thus, the distribution of perceived relative risk was positively skewed with more than 90% of the sample at the mid-point or lower. This finding is consistent with existing literature on underestimation of health risk, or an optimistic bias, as coined by Weinstein (1980). Such a bias, not necessarily confined to health outcomes, reflects an overestimation of positive outcomes and underestimation of negative

outcomes (Sharot, 2011). Researchers suggest that about 80% of the population tends to be optimistically biased (Sharot, 2011). With regard to outcomes, such optimism may be beneficial for mental and even physical health (e.g., lack of positive expectancy is associated with depression and anxiety, and optimists tend to live longer); on the other hand, a propensity for underestimating risk may also reduce the likelihood of engaging in healthy behaviors (Sharot, 2011). Further analysis of our data is consistent with the optimistic bias interpretation, as general trait optimism was negatively associated with the relative risk item described earlier, as well as perceived recurrence and mortality risk overall. However, contrary to the potential dangers of optimism discussed above, we found that optimism was actually positively associated with adherence to cancer prevention recommendations and unrelated to actual risk of recurrence; thus, in our sample, optimism appeared to have only salubrious effects.

Two seemingly contrasting pieces of information are that most of the sample reported that they perceived themselves to be at the same or lower risk of recurrence as others like them yet the sample's average discrepancy of perceived and objective risk suggested an overall tendency to overestimate the chances of recurrence. In contrast to the more than 90% who were at the mid-point or below on the relative risk item, 46.5% of the sample was at 0 or below on the perceived-objective risk discrepancy item (indicative of being accurate or perceiving less risk than the objective estimate). Although this appears to be contradictory, there are a few possible explanations for these findings. First, it is noteworthy that these variables were correlated ( $r = .36, p < .001$ ). One interpretation is that, although survivors

might consider themselves to be at the same or lower risk as other survivors like them, they may nonetheless overestimate the numerical percentage associated with the risk status of both themselves and others. Additionally, it may be the case that a subsample who perceive higher relative risk than other survivors like them may be responsible for much of the over-estimation of risk values.

Another entirely different population of cancer survivors includes those who accurately appraise themselves to be at a high risk of recurrence. This population poses a unique challenge for providers. As discussed earlier, one of the unique aspects of fear of recurrence is that, although it is an anxiety construct, unlike most anxiety disorders, in some cases, the fear in fear of recurrence may not be based on "erroneous" estimations of risk but instead based on true, elevated risk (e.g., Nielsen, Nordestgaard, & Bojesen, 2012). Unfortunately, although not at a higher risk for other types of cancers, cancer survivors are at an elevated risk of recurrence of the same cancer, and some survivors (e.g., hormone receptor negative) are at an even higher risk than their otherwise similar counterparts. Again, there are numerous potential ways one might intervene with this population. However, one finding we again point to in the present study is the role that acceptance played in mitigating the ill effects of fear of recurrence on functional impairment. Acceptance-based strategies may be a particularly useful approach for working with this unique cancer subpopulation. We also again highlight the research discussed above on the MBSR and the AFTER interventions, which may be particularly useful with these higher-risk individuals.

Another clinical question concerns at what point fear of recurrence becomes problematic. With our data, the vast majority of relationships that we observed were linear and unmoderated effects of fear of recurrence. The only non-linear relationship we found was between fear of recurrence and oncology office visits, and we could not replicate this finding with the FCRI or CARS. Thus, while this finding is intriguing, it is difficult to say whether it is a reliable finding and, furthermore, how to best capitalize on it given a lack of replication in existing measures.

Furthermore, the majority of behavioral outcomes assessed in this study were continuous (e.g., degree of functional impairment, number of health care visits), which also makes it difficult to assess a clear cut point where an outcome reaches clinical significance. Two dichotomous outcomes that we included in our study were mental health counseling and mental health medications. Although certainly not a comprehensive test of clinical significance, for exploratory purposes, we evaluated the mean FCRI total score and CARS overall fear subscale score for those who had/had not received a mental health intervention since their cancer diagnosis. The mean differences were relatively small but significant (each scale ranges from 1 to 5 in our sample).

For the FCRI, the mean total score for those who received counseling was 2.63, compared to 2.29 for those who did not receive counseling,  $t(295) = -4.03$ ,  $p < .001$ . Likewise, the mean score for those who were prescribed psychotropic medications was 2.61, compared to 2.27 for those who were not,  $t(295) = -4.38$ ,  $p < .001$ . For the CARS overall fear subscale, the mean score for those who received

counseling was 2.87, compared to 2.51 for those who did not receive counseling,  $t(295) = -2.11, p = .04$ . Likewise, the mean score for those who were prescribed psychotropic medications was 3.00, compared to 2.44 for those who were not,  $t(295) = -3.58, p < .001$ . Although not conclusive, we hope that this information may help researchers move towards understanding more about levels of fear of recurrence most likely to lead to clinically significant problems.

#### **4.5 Implications for Measurement**

Our goal was to test a theory of fear of recurrence and to engage in construct validation of this important variable. To do so, we selected a small number of theory-consistent items, but our aim was not to develop or replace another measure. Nonetheless our research on the construct of fear of recurrence may lead one to wonder whether the findings from the present study would extend to existing measures of fear of recurrence.

Overall, we see the FCRI as a measure that is particularly consistent with our cognitive-emotional theory of fear of recurrence. This measure appears to assess broad, contextual features—what some might consider to be antecedents (e.g., triggers) and consequences (e.g., functional impairment) of fear of recurrence itself. Nonetheless, the data that comes from such a measure can provide rich clinical information for providers. Furthermore, this measure was developed based on a cognitive-behavioral conceptualization of fear of recurrence (Lee-Jones et al., 1997) which also influenced our model.

A second fear of recurrence scale we administered is the CARS. This measure has two sections, the first of which (the overall fear subscale) is also in line with the cognitive-emotional theory of fear of recurrence tested in this study. The second section that investigates the specific content of survivors' worries provides more detailed information about a survivor's fears (that again would provide rich data to providers) and thus focuses primarily on the cognitive component of fear of recurrence.

To explore the generalizability of our findings to these measures, we ran supplementary analyses to evaluate the concurrent validity of the FCRI and CARS with regard to the behavioral outcomes assessed in this study (e.g., health care utilization, physical self-examination, etc.). First, we found that the latent fear of recurrence factor used in the present study was highly correlated with the CARS overall fear scale ( $r = .94, p < .001$ ). We did not attempt to correlate the fear of recurrence factor with the FCRI total score as these contain overlapping items, but the FCRI total score was also highly correlated with the overall fear scale of the CARS ( $r = .81, p < .001$ ).

We also found the FCRI and CARS were largely able to predict these behavioral outcomes assessed in this study, with some subscales being more reliable predictors than others. On the FCRI, the total score as well as the triggers, severity, distress, and impairment subscales were each consistently associated with our measured behavioral outcomes, whereas the insight, reassurance, and coping subscales inconsistently predicted behavioral outcomes. On the CARS, the overall fear scale as

well as the health worries, role worries, and death worries subscales were each consistently associated with the behavioral outcomes, while the womanhood worries subscale was less consistent in its associations with behavioral outcomes. Taken together, these findings lend support to the overall utility of these existing measures, but it also points to those subscales that are most useful for predicting relevant outcomes. The insight, reassurance, and coping subscales of the FCRI and the womanhood worries subscale of the CARS may warrant further attention to determine their overall fit with fear of recurrence measurement.

#### **4.6 Strengths and Limitations of the Present Study**

Each of the findings from this study should be considered within the context of the strengths and limitations of the research design. We employed a number of approaches that we felt would enhance our ability to test the research questions, detect effects and test relationships, and generalize to a broad population. We recruited a relatively large sample of early-stage breast cancer survivors that gave us adequate statistical power necessary to test our research questions. Our sample was heterogeneous with respect to age, education, income, work status, and time since diagnosis. In addition, we utilized sophisticated latent variable-based statistical approaches that allowed us to examine relationships between constructs and variables of interest in nuanced and creative ways. By utilizing latent variable modeling, we were able to empirically evaluate fit of various items with an overall conceptual model. Furthermore, by using ESEM and bifactor modeling in particular, we were able to address research questions that cannot be answered by traditional CFA

approaches. These flexible modeling strategies allowed to us to more faithfully assess the relationships between similar constructs and to examine relationships with both common and unique facets of multidimensional constructs. However, the study is also subject to a number of limitations that should be noted.

One interesting point is that we aimed to study an anxiety-related construct when anxiety is often characterized by avoidance. As a result, one might expect that those highest in fear of recurrence might have been reluctant to think about and answer questions related to cancer and, thus, less likely to participate in the study. In the interest of informed consent, we were open with potential participants about the fact that the research was focused on fear of cancer recurrence, as many questions were directly about this topic. However, this may have led some individuals high in fear of recurrence to decline to participate in the study. Thus, one potential limitation of the study is sampling and, therefore, generalizability of the results to the full population of breast cancer survivors.

Unfortunately, this is a common issue in research of this nature and impossible to avoid entirely. To the best of our ability, we aimed to recruit even those individuals who might be high in fear of recurrence or avoidance. Our recruitment efforts were as exhaustive as possible while still being respectful of potential participants. Each potentially eligible individual was sent a letter informing them of the research, and a research assistant subsequently followed up by phone. We made at least three calls to each participant (or until they declined) before considering them a passive refusal. We implemented the same degree of thoroughness after a participant agreed to participate

(e.g., making phone outreach attempts when participants had not returned consent forms or surveys, re-sending survey links via e-mail). Thus, every effort was made to recruit and retain avoidant (and less conscientious) participants.

A review of study variables assessing severity and distress suggest that we were able to obtain acceptable variability in the responses from participants in our sample. The mode for initial cancer diagnosis distress was a 10 out of 10 (i.e., "very distressing"). The FCRI total score and severity subscale were each normally distributed with means near the scale middle anchor (2.66 and 2.36 out of 5, respectively). With regard to the avoidance question specifically, our participants were not particularly avoidant (64.7% rarely or never avoid cancer reminders); however, 4.3% reported avoiding cancer reminders "all the time," 12.7% reported avoiding cancer reminders "most of the time," and 18.3% reported avoiding cancer reminders "sometimes." Thus, although the sample were mostly non-avoidant, it included many individuals (106 out of 300) that were moderately to severely avoidant, and we appeared to have good variability in measures of distress.

In this study, we assessed a number of relationships between variables that have not been tested previously in the literature. Balancing our large scope with an awareness for participant burden, we could not assess every variable as thoroughly as would be ideal, especially for those variables that do not have clear, "gold-standard" measures (e.g., goal-striving, avoidance). Therefore, we hope that future research may further examine these relationships and explore more fine-tuned ways of measuring some of the variables in the study, such as engagement and avoidance.

Another important point is that many of the variables in this study, including our "behavioral outcomes" (e.g., self-examination, health care utilization), were based on self-report. The limitations of self-reported data have been extensively enumerated. As mentioned earlier, one such limitation is the opportunity for response styles to affect the observed relationships between variables (e.g., Van Vaerenbergh & Thomas, 2012). On the one hand, many of the variables assessed in this study are best captured by self-report, as they reflect an internal, subjective experience (e.g., fear of recurrence, anxious apprehension). We also attempted to incorporate non-self-report data by extracting clinical information for each participant (e.g., clinical characteristics, unbiased risk estimates, etc.) that we used to supplement self-report data. Nonetheless, we hope that future research builds upon the limitations of this study by utilizing other forms of assessment such as additional forms of corroborating evidence (e.g., additional records to assess the frequency of doctor visits), observer reports (e.g., observer data collected from an identified support person close to the survivor), physiological data, or behavioral observation.

Additionally, we utilized a novel method of exploring risk discrepancy in which we compared participants' perceptions of risk to an objective estimate of risk. To do so required us to calculate each participant's risk based on clinical information. We consulted oncology experts to help us develop our method, but we acknowledge that our approach was a first step in this line of research and therefore imperfect and open to areas of improvement. For example, while we obtained detailed information about each survivor's chemotherapy regimen, the variety of drug combinations that

exist, and the constant updating of these medical interventions, make our categorization of survivors into certain treatment categories imperfect. The tool is also based on population-based risk, as opposed to individual risk. The risk calculating tool also is not perfect, even for its intended usage with individual patients. For example, it does not take into account factors like whether a patient is human epidermal growth factor receptor 2 (HER2) positive, which does affect risk. According to one study assessing breast cancer patients with node-negative tumors 1 centimeter or smaller, patients with HER2 positive tumors had 5.09 times the rate of recurrence and 7.81 times the rate of distant recurrence at five years compared to HER2 negative tumors (Gonzales-Angulo et al., 2009). However, these patients are also likely to receive adjuvant treatment like Herceptin, which has been shown to promote long-term survival among patients with HER2 positive breast cancer (e.g., Mayer et al., 2015) and which was also not accounted for in our Adjuvant! Online-based risk estimates. Psycho-oncologists may use different risk-calculating tools based on different patient features; however, we were advised that this approach would be the best option to apply to a large number of participants, although it does not take into account all such nuances. We opted to use the same procedure across all participants so as not to introduce any additional systematic variability in our approach, but we note that there are likely more accurate ways of obtaining a particular survivor's recurrence risk.

An additional point is that we used a tool that was designed to be used prospectively (i.e., to help medical oncologists select adjuvant treatments based on

their relative additive value) in a retrospective way. One limitation of this method is that it does not incorporate any adjustments in risk that may occur over the time that has passed since diagnosis. For example, most recurrences within 10 years from diagnosis occur within the first five years (Cheng et al., 2012). This is particularly true for those survivors who were Stage III (vs. Stage I or II) with negative hormone receptor status and poorly differentiated histologic grade tumors (Cheng et al., 2012). Thus, we used the most highly recommended approach available to us to evaluate recurrence risk for a large heterogeneous sample of survivors. In doing so, we took into account each survivor's unique adjuvant therapy received (e.g., the specific type of chemotherapy received) and based our estimation on a number of clinical features including tumor size, tumor grade, and number of positive nodes. While this was an important step in comparing perceived versus objective risk, we hope that future research will build upon this method and be able to even more accurately capture survivors' recurrence risk.

Another important limitation is that, although we examined fear of recurrence as a "predictor" of behavioral "outcomes," in fact, we cannot say that such relationships are of a causal nature. We measured the "outcomes" and "predictors" simultaneously, and, thus, we cannot establish the direction of effects. In addition, it is not possible to rule out all potential third variables that might explain these relationships. For example, one possibility is that the relationship between fear of recurrence and increased contact with oncology providers is the result of more health care complications or physical complaints. We do not have a way of assessing the

necessity of the medical appointments that survivors had, so it is impossible to say the extent to which such appointments were medically indicated.

One way that we can rule out the likelihood of this possibility is to control for other factors including stage, age, and years since diagnosis. When controlling for each of these variables, we found that fear of recurrence remained a significant predictor of the number of calls and visits to oncology providers in the past year, usage of psychotropic medications, receipt of advice to seek out mental health treatment, disengagement, flourishing, self-examination, and functional impairment. These findings provide support for the interpretation that fear of recurrence specifically, and not just greater severity, account for these outcomes. However, we found that fear of recurrence was no longer a significant predictor of mental health counseling and was only a marginally significant predictor of the occurrence of an oncology visit in the past three months when controlling for these variables.

Finally, our sample was comprised of primarily White breast cancer survivors, the household income of participants was relatively high, and there were fewer Stage III survivors in our sample than earlier stages. Therefore, it is unclear how much our results would generalize to a more racially/ethnically diverse sample that is more economically disadvantaged and of primarily more advanced stage. We hope that further research will continue to explore the generalizability of these findings to these and other populations that may be underrepresented in research.

#### **4.7 Future Directions**

The results of this study leave us with many new questions that we hope future research will undertake. Given the relative novelty of and growing interest in fear of recurrence, as well as its antecedents and consequences, we expect that research will continue to develop in this important area. One question concerns the generalizability of our findings to other cancer sites. In the present study, we focused exclusively on breast cancer survivors, so we are interested in future research on what aspects of fear of recurrence are consistent across cancer sites and which elements may differ by site. Additionally, we chose to focus on survivors diagnosed with early-stage cancer, defined as Stages 0 to IIIA; however, an open question concerns whether fear of recurrence looks the same in samples of survivors with more advanced illness. Some definitions of fear of recurrence highlight fear of cancer *progression* as well as fear of recurrence (e.g., Vickberg, 2003). Future research is needed to determine if these processes are comparable or distinct.

As an extension of this line of inquiry, we also wonder about fear of recurrence processes in sufferers of other illnesses. Certainly, individuals who are at risk for other forms of illness recurrence could just as likely be anxious in a manner akin to fear of cancer recurrence, and we hope future research will tell us more about whether those processes are identical to fear of cancer recurrence or whether there are systematic differences.

We also acknowledge that our study gave only a snapshot of the complex survivorship experience of the participants in our study. We are interested to know

more about the stability of fear of recurrence and how fluctuations over time in fear of recurrence may affect behavioral outcomes such as those included in this study.

Recently, researchers have begun to examine the temporal course of fear of recurrence and changes that occur as survivors approach medical screenings that trigger fears of recurrence (McGinty et al. 2015). Additional research in our lab is also ongoing to examine cancer-related processes unfolding on a daily level among survivors and their partners (e.g., Otto, Laurenceau, Siegel, & Belcher, 2015; Pasipanodya et al., 2012) including fear of recurrence (e.g., Pasipanodya, Laurenceau, Siegel, Otto, & LoSavio, manuscript submitted for publication). We hope these new lines of research will shed more light onto the potentially dynamic course of fear of recurrence.

As our understanding of the construct of fear of recurrence deepens, we also hope that future research may involve more inquiry into interventions for this problem. We have highlighted potential clinical interventions stemming from our findings, but we expect that future research focused specifically on those interventions that are most effective in helping survivors cope with recurrence anxiety will better answer these questions and more.

#### **4.8 Concluding Comments**

Overall, this study represents a step in the theory-testing and construct validation of fear of cancer recurrence, one of the top concerns for cancer survivors today. Our results lend support to the uniqueness of this anxiety-based construct and to its predictive power for behavioral outcomes relevant to breast cancer survivors. We feel that these results demonstrate the importance of this construct and its worthiness

of further study, and we look forward to future research on this experience that affects many cancer survivors.

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**Appendix A**

**INSTITUTIONAL REVIEW BOARD APPROVAL FORMS**



Institutional Review Board  
FWA00006557

Helen F. Graham Cancer Center  
West Pavilion - Suite 2350  
4701 Ogletown Stanton Road  
Newark, DE 19713

302-623-4983 phone  
302-623-4989 phone  
302-623-6863 fax

## MEMORANDUM

Steven Kushner, MD  
Chairman, IRB #1  
Gary Johnson, PhD  
Chairman, IRB #2  
Jerry Castellano, Pharm.D, CIP  
Corporate Director  
Janet Leary-Prowse, MSEd, CIP  
IRB Education Specialist  
Heidi Derr, BA, CIP  
IRB Regulatory Affairs/Auditor  
Sonia Martinez-Colon  
Executive Assistant  
Judy Hatt, BS  
Administrative Assistant  
Lauren Pigeon, CPHT  
Administrative Assistant

**DATE:** April 9, 2013  
**TO:** Scott Siegel, PhD  
Oncology Research  
Christiana Hospital  
**FROM:** Sonia Martinez-Colon *SMC*  
**RE:** **CCC# 33052 - Evaluating the Construct of Fear of Recurrence among Breast Cancer Survivors: (DDD# 602243)**

This is to officially inform you that your protocol was approved by Expedited Review per *45 CFR 46.110(F) (7)*, by Jerry Castellano, Pharm.D, CIP, Corporate Director of Christiana Care Health System Institutional Review Board, on **04/09/2013**. Approval was granted for a period of one year, from **04/09/2013** through **04/08/2014**.

The above stated CCC# (Christiana Care Corporation number) has been assigned to your research. That number, along with the title of your study, must be used in all communication with the IRB Office.

Changes in this protocol after the initial approval may not be initiated without Institutional Review Board review and approval, except where necessary to eliminate apparent immediate hazards to the human subject. Also, if you encounter any adverse effects or deaths that must be reported to the company and the FDA, the committee must be so informed immediately by phone.

In addition, a periodic review of this protocol will be conducted in six months to a year from the above approval date. At that time, you will be required to complete a review form with all available information collected to date on your protocol.

A final requirement is that you notify the Institutional Review Board when this protocol is completed, and all results are to be summarized for the committee's review.

If you have any questions, please contact the IRB Office.



RESEARCH OFFICE

210 HULLIHEN HALL  
UNIVERSITY OF DELAWARE  
NEWARK, DELAWARE 19716-1551  
PH: 302/831-2136  
FAX: 302/831-2828

DATE: July 13, 2015

TO: Stefanie LoSavio  
FROM: University of Delaware IRB

STUDY TITLE: [779573-1] Evaluating the Construct of Fear of Recurrence among Breast Cancer Survivors

SUBMISSION TYPE: New Project

ACTION: ACKNOWLEDGED  
APPROVAL DATE: July 13, 2015

REVIEW TYPE: Administrative Review

REVIEW CATEGORY: *CCHS is the IRB of Record.*

Thank you for your submission of New Project materials for this research study. The University of Delaware IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Administrative Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the study and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the study via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the signed consent document.

Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure.

All SERIOUS and UNEXPECTED adverse events must be reported to this office. Please use the appropriate adverse event forms for this procedure. All sponsor reporting requirements should also be followed.

Please report all NON-COMPLIANCE issues or COMPLAINTS regarding this study to this office.

Please note that all research records must be retained for a minimum of three years.

Based on the risks, this project requires Continuing Review by this office on an annual basis. Please use the appropriate renewal forms for this procedure.

**Appendix B**

**LIST OF STUDY MEASURES**

## Study Items Completed by Participants

What is your date of birth?

What is your racial/ethnic background? Select all that apply.

*White, Black or African American, Hispanic/Latina, Asian, American Indian or Alaskan Native, Native Hawaiian or Pacific Islander, Other (please specify)*

How far did you go in school?

*Did not complete high school, High school graduate or equivalent, Completed some college, Completed an undergraduate college degree (associate's or bachelor's degree), Completed some graduate school, Completed a graduate degree*

What is your current occupational status?

*Not working, Working part-time, Working full-time*

What is your yearly family income?

*10,000 or less, 10,001-20,000, 20,001-40,000, 40,001-60,000, 60,001-80,000, 80,001-100,000, More than 100,000*

What is your current relationship status?

*Married; Engaged; In a committed relationship; Single, never married; Single, divorced/separated; Single, widowed*

Do you have any children?

*No, Yes*

How long ago were you diagnosed with breast cancer? Please round to the nearest year.

*0 years ago, 1 year ago, 2 years ago, 3 years ago, 4 years ago, 5 years ago, 6 years ago, 7 years ago*

Do you have any other current medical illnesses?

*No, Yes*

*If you have any other medical illnesses:*

Please list your other current medical illnesses below.

How distressing were the following aspects of your illness and treatment?

Initial diagnosis

*0 Not at all distressing to 10 Very distressing*

The following questions ask about your thoughts about your risk of having breast cancer again. Please answer each question even if you are not sure about your risk.

What do you think your chance is of having breast cancer again (including a recurrence of the same breast cancer OR a new breast cancer) within the next 10 years? Please choose a number between 0% (no chance having a breast cancer again) and 100% (definitely will have breast cancer again).

Overall, how do you think your chance of developing breast cancer again compares to that of other breast cancer survivors like you (e.g., same age, stage, treatment etc.)? *My chances of developing breast cancer again are much lower, My chances of developing breast cancer again are somewhat lower, My chances of developing breast cancer again are about the same, My chances of developing breast cancer again are somewhat higher, My chances of developing breast cancer again are much higher*

If you were to experience a recurrence of cancer, how would you rate your ability to cope with it?

*1 I would not be able to cope with it, 2, 3, It would be difficult to cope, but it would be manageable, 4, 5 I am confident I could cope*

The following questions will ask you about recent interactions you have had with your medical providers. Please pay close attention to the timeframe, the type of medical provider, and the type of contact that you are asked about. In particular, you will be asked to report on the number of *visits* and *phone calls* you have made. You will be asked about the timeframe of the *last three months* and the *last year*. Finally, you will be asked about contact with “*oncology medical providers*,” your “*primary care physician*,” and any “*other medical providers*” you may see. “Oncology medical providers” may include your medical oncologist, radiologist, surgeon, etc.

Have you had any visits to an oncology medical provider's office in the PAST 3 MONTHS?

*No, Yes*

Have you had any visits to your primary care physician's office in the PAST 3 MONTHS?

*No, Yes*

About how many visits did you make to an oncology medical provider's office in the past year? (If you saw multiple different types of oncology medical providers, please add up the total number of visits across the oncology providers.)

About how many visits did you make to your primary care physician's office in the past year?

The next set of questions will ask you about phone calls to the offices of your medical providers. In this section, you should NOT include phone calls that were made exclusively to schedule an appointment *if you did not discuss your health or symptoms on the phone*, and as long as that appointment was included in the preceding section on office visits. However, if you made a call to the provider's office and spoke with someone in the office or left a message, and the interaction involved the discussion of physical symptoms or your health, you should count it here. For example, you might have called with a question or called to report about a symptom you were experiencing. Please count up the number of such phone interactions and include them in this section.

Did you make any phone calls to an oncology medical provider's office in the PAST 3 MONTHS?

*No, Yes*

Did you make any phone calls to your primary care physician's office in the PAST 3 MONTHS?

*No, Yes*

About how many phone calls did you make to an oncology medical provider's office in the past year? (If you called multiple different types of oncology medical providers, please add up the total number of calls across the oncology providers.)

About how many phone calls did you make to your primary care physician's office in the past year?

Please answer the following questions about mental health service utilization.

*No, Yes*

1. At any point after your cancer diagnosis, did you seek out mental health services such as psychotherapy or counseling?
2. Since your cancer diagnosis, have you taken or been prescribed any psychotropic medications--that is, medications that are intended to affect mood or behavior (e.g., antidepressants, anti-anxiety medications)?
3. Since your cancer diagnosis, has anyone (e.g., relative, friend) suggested to you that you may benefit from mental health services or psychiatric medication?

How often do you check your body for signs or symptoms of cancer?

*1 Never, 2 A few times a year, 3 About once a month, 4 About once a week, 5 A few times a week, 6 Daily, 7 A few times a day, and 8 Several times a day.*

Please indicate whether or not you have engaged in any of the following changes during the past year. If you have engaged in an activity, please check the box beside the item.

1. Developed new relationships with people who have new and interesting ideas or lifestyle
2. Entered into a new romantic relationship
3. Got married/re-married
4. Began a new job or volunteer position
5. Started a new business
6. Pursued an educational goal/advanced my education/took a new training course
7. Joined a social organization
8. Developed a new interest, hobby, or recreational activity
9. Purchased a new car
10. Purchased new property or a new home
11. Other major purchase (e.g., boat, art collection, etc.)
12. Completed or planned a renovation or major redecoration of home
13. Acquired a new pet
14. Planned a vacation
15. Made new financial investments (e.g., stocks, bonds)
16. Started or contributed to a retirement plan
17. Planned to expand my family/make an addition to my family (e.g., have/adopt a child)
18. Made resolutions to live a healthier life or set new personal goals

Please indicate whether or not you have engaged in any of the following changes during the past year. If you have engaged in an activity, please check the box beside the item.

1. Gave away many personal belongings
2. Cancelled future plans or purchases (e.g., vacation, home renovation, other major purchase)
3. Spent much less time devoted to a recreational activity (e.g., hobby)
4. Left my job or volunteer position (other than planned retirement)

5. Sold off financial shares or cashed in investments (e.g., stocks, company share, retirement plan, reverse mortgage, personal collections)
6. Pulled away from personal relationships (e.g., broke off relationship with a romantic partner or distanced self from a friend)
7. Gave away/found a new home for my pets

Below is a list of changes that you may or may not have made to your life since your cancer diagnosis. Please indicate whether you have made any of the following changes since your cancer diagnosis and, if so, to what extent.

Note: If you were already engaging in a behavior before your cancer diagnosis and made no further change (e.g., if you already refrained from smoking), then you should indicate "I did not make a change" for that item. However, if you were already engaging in a behavior but you *increased* your engagement in that behavior since your cancer diagnosis (e.g., you already exercised but you increased your regular engagement in physical activity following your diagnosis), then you should indicate it as a change and rate the extent to which you made a change (e.g., "a little").

*1 I did not make a change, 2 A little, 3 Somewhat, 4 Moderately, 5 Very much*

1. Lost weight (if you were overweight)
2. Increased engagement in moderate or vigorous intensity physical activity each week
3. Limited engagement in sedentary behavior such as sitting, lying down, watching television, or other forms of screen-based entertainment
4. Altered my diet to consume foods and beverages in amounts that help achieve a healthy weight
5. Limited consumption of red and/or processed meat
6. Altered diet to eat at least 2.5 cups of vegetables and fruits each day
7. Chose more whole grains instead of refined grain products
8. Reduced consumption of alcoholic beverages
9. Cut back on or quit smoking
10. Worked on developing a stronger social support network
11. Engaged in more self-care with regard to mental health (e.g., reduced stressors in my life, engaged in more relaxation activities, etc.)
12. Made an effort to spend more time with family and/or friends
13. Put more time into pleasurable/social activities or became more involved with personally-important projects

*Existing questionnaires administered:*

Mood and Anxiety Symptoms Questionnaire (MASQ; Clark & Watson, 1991)

PTSD Scale—Self-Report for DSM-5 (PS-SR-5; unpublished measure with permission by Edna B. Foa)

Penn State Worry Questionnaire (PSWQ; Meyer et al., 1990)

Intolerance of Uncertainty Scale (IUS-12; Carleton et al., 2007)

Fear of Cancer Recurrence Inventory (FCRI; Simard & Savard, 2009)

Concerns About Recurrence Scale (CARS; Vickberg, 2003)

Flourishing Scale (Diener et al., 2009)

Acceptance and Action Questionnaire-II (AAQ-II; Bond et al., 2011)

Select items from the Generalized Anxiety Disorder Questionnaire-IV (GADQ-IV; Newman et al., 2002).

Select, adapted items from the Illness Attitudes Scale (IAS; Stewart & Watt, 2000)

Life Orientation Test-Revised (LOT-R; Scheier, Carver, & Bridges, 1994)