FEAR OF CANCER RECURRENCE: TESTING A COGNITIVE FORMULATION ACROSS TIME IN WOMEN FACING OVARIAN CANCER

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Lindsey Torbit
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Fear of Cancer Recurrence: Testing a Cognitive Formulation Across Time in Women with Ovarian Cancer

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Lindsey Torbit

Psychology

Ryerson University

Abstract

Background: Lee-Jones and colleagues (1997) have proposed a comprehensive cognitive model of fear of cancer recurrence (FCR), however little research has utilized or fully tested this conceptual model. Additionally, the cross-sectional nature of most studies limits our understanding of the trajectory of FCR over time, and longitudinal research is greatly needed. **Method:** Patients completed assessment measures at baseline (Time 1) and three months post-baseline (Time 2). The three aims of this study were to (1) test the cognitive model of FCR within an ovarian cancer population; (2) examine model stability; and (3) test the predictive validity of the model. **Results:** An exploratory factor analysis (EFA) suggested a more parsimonious four-factor model relative to Lee-Jones et al.'s suggested model. Using the results of the EFA, structural equation modeling (SEM) was used to analyze the data-driven model, with findings revealing excellent model fit at Time 1, χ^2 (60, N=283) = 130.48, p< .001, χ^2/df = 1.84, CFI = 0.95, RMSEA = .06, SRMR = .06. This same model was examined at Time 2, with findings revealing acceptable model fit; χ^2 (60, N=201) = 121.15, p < .001, χ^2/df = 2.02, CFI = 0.93, RMSEA = .07, SRMR = .07, thus confirming that configural invariance was met. Tests of predictive validity indicated that using the components of FCR at Time 1 to predict consequences at Time 2 resulted in adequate model fit, χ^2 (84, N=283) = 167.17, p < .001, CFI = 0.94, RMSEA = .06, SRMR = .07, χ^2/df = 1.99; however, the regression paths from the

emotional experience and cognitive appraisals were not significant predictors of behavioural responses at Time 2. **Discussion:** Findings demonstrated that the emotional experience of FCR may be far more complex for ovarian cancer patients than previously suggested which has important treatment implications. The current study is the first to evaluate the relative stability of the components of a data-driven model of FCR, with results revealing that the majority of ovarian cancer patients experience FCR, which is stable across a three-month period. Findings suggest that screening for FCR would be beneficial across the cancer experience.

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Overview

Fear of cancer recurrence (FCR) is one of the most common psychological disturbances reported by cancer patients (Baker, Denniston, Smith, & West, 2005). It has also been documented as the most prevalent unmet need in cancer survivors with 22% to 87% of survivors reporting moderate to high levels of FCR (Crist & Grunfeld, 2013; Simard, Savard, & Ivers, 2010). FCR, especially when severe and persistent, is associated with several negative outcomes including greater general psychological distress, impairments in functioning and lower quality of life, as well as increased use of health care services (Crist & Grunfeld, 2013). Although the current literature lacks a widely accepted definition of FCR, the definition most often adopted by researchers is "fear that cancer could return or progress in the same place or another part of the body" (Simard, Sivard & Ivers, 2010; Vickberg, 2003), which suggests that FCR is relevant across the cancer trajectory.

Although FCR is a common experience in many different kinds of cancer, because of the unique characteristics of ovarian cancer, as well as the high rates of recurrence, FCR is particularly significant for this group of patients. A growing body of literature indicates that because of poor prognosis and intensive treatment protocols, ovarian cancer patients often experience high distress at the time of diagnosis and during treatment (Costanzo, Lutgendorf, Rothrock, & Anderson, 2006). In addition, risk of recurrence is high (30-40%) among patients with early-stage ovarian cancer (Young et al., 1990), and more than 70% of patients with advanced ovarian cancer will experience disease recurrence (Romero & Bast 2012). Not surprisingly, a substantial proportion of ovarian cancer survivors report experiencing fears of future diagnostic tests (40%) and recurrence (20%; Wenzel et al., 2002). As such, ovarian cancer patients represent a particularly relevant and important population in which to examine FCR.

Despite a burgeoning literature on FCR, our knowledge is limited in several important ways. First, the extant studies are significantly lacking in theoretical foundation, which is of critical importance for enhancing research that can be translated into improved clinical care. Lee-Jones, Humphris, Dixon and Bebbington Hatcher (1997) have proposed a comprehensive cognitive model of FCR to address this gap, however little research has utilized or fully tested this conceptual model. Second, the cross-sectional nature of most studies limits our understanding of the trajectory of fear of recurrence over time, and longitudinal research is greatly needed. The present study aims to address these limitations.

Background: Fear of Cancer Recurrence

The first systematic review of the literature on FCR was published in 1997 by Lee-Jones and colleagues. At that time, psycho-oncological researchers had recognized that FCR was an important issue, but in-depth investigation was absent. This review found that FCR research had been primarily focused on breast cancer patients, which reduced the ability to generalize to other people with cancer. Furthermore, the review reported that the evidence regarding the influence of time since diagnosis on FCR was contradictory (Meyer & Aspegren, 1989; O'Neil, 1975). Lastly, the review asserted that FCR questions were often included as part of a larger scale study concentrating on other research aims, and the lack of investigation of FCR as a separate and central phenomenon significantly limited our understanding. In response to the reported shortcomings in the literature, the authors proposed a cognitive formulation of FCR.

The Cognitive Model of FCR

The Cognitive Model of FCR proposed by Lee-Jones and colleagues (1997) integrates elements from cognitive behavioural theory and past research. The comprehensive model outlines the cognitions, beliefs and emotions believed to comprise FCR, as well as the antecedents and consequences of FCR. The FCR model is hypothesized to be bi-directional, for example, resulting consequences also exert an influence on both cognitive processes and the interpretation of antecedents. In accordance with Leventhal's Common Sense Model of Illness, Lee Jones and colleagues posit that an individual's FCR will vary according to his or her 'illness representation.' The "illness representation" is defined as the way individuals understand what their illness is, its causes, its consequences, how long it will last, and whether it can be cured or controlled. This understanding is often not medically validated, but based on personal experience with physical

symptoms and emotions, social influences, and interactions with healthcare providers (Browing et al., 2009; Leventhal, 1970; Leventhal, Meyer, & Nerenz, 1980).

The cognitive model of FCR presented in Figure 1 proposes that stimuli, both internal and external, play a role in activating cognitive responses associated with FCR. Internal stimuli include somatic cues (e.g., physical symptoms) that are appraised and interpreted as a reminder of the disease of as a symptom of recurrence (Easterling & Leventhal, 1989; Northouse, 1981). External stimuli include cues from the environment that are associated with the disease, such as doctors' appointments or exposure to media related to cancer, which can trigger thoughts and anxiety about recurrence (Easterling & Leventhal, 1989; Northouse, 1981). Additionally, family members may play a role in triggering concerns about recurrence, by asking questions about health and illness-related issues, or by becoming upset or uncomfortable when these topics are raised by the patient (Mesters et al., 1997). The model proposes that FCR is comprised of cognitions and emotions. Cognitions include anxious thoughts about recurrence, doubts that the cancer has been completely eradicated, and worry that one's doctor is not checking carefully enough or providing adequate monitoring of the cancer (Mahon, 1991; Northouse, 1981; Wyatt et al., 1993). Patients who appraise themselves to be at higher risk of recurrence will experience more emotional distress by the perception of benign symptom cues, such as lymphadema (Easterling and Leventhal, 1989). Additionally, a patient's past cancer experience will impact one's level of anxiety and concern about cancer returning (Leventhal et al., 1992). Indeed, research suggests that women who have had a prior cancer recurrence or second cancer diagnosis tend to report higher levels of FCR (Lebel et al., 2007; Rosmolen et al., 2010; Shim et al., 2010; Simard & Savard, 2009; Ullrich et al., 2003).

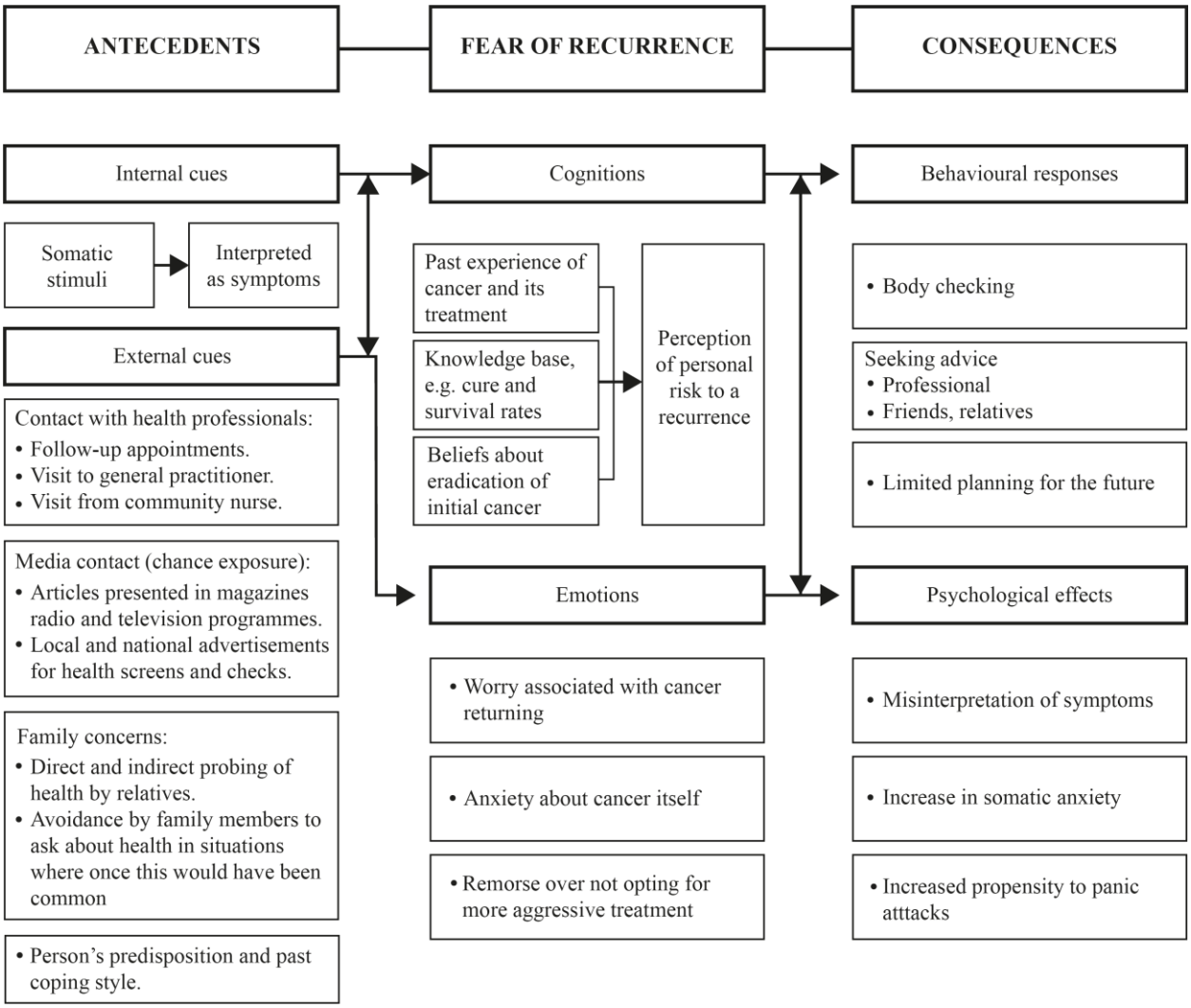

Figure 1. The cognitive model of FCR proposed by Lee-Jones and colleagues (1997).

The model outlines several consequences of high FCR that have been documented in the literature. First, the model posits that as a response to FCR, individuals will engage in excessive body checking for signs indicative of disease and seek reassurance from physicians and friends or relatives to manage their anxiety. This premise is based on research demonstrating high FCR to be associated with anxious preoccupation and personal checking behaviour (Lasry & Margolese, 1992), as well as increased frequency of unscheduled medical appointments (Lee-Jones et al., 1997). Second, concerns about recurrence may result in limited planning for the future (Northouse, 1981). Indeed, high FCR has been shown to be associated with more hopelessness about the future (Lee-Jones et al., 1997), and may cause patients to refrain from planning too far ahead or setting long-term goals in the event that their health status changes.

Despite the fact that the cognitive model was developed to guide future research, this fundamental theoretical formulation as a whole remains untested. Since this first comprehensive review, research in the area of FCR has increased considerably, but also haphazardly. Although empirical evidence for the cognitive model of FCR as whole is lacking, discrete components of the model have been examined in individual FCR-related studies over the past two decades. This includes a recent study by Custers and colleagues (2017) who evaluated select components of the model using separate mediation analyses in a sample of disease-free breast cancer survivors. The study used twelve conceptual models to examine four different types of triggers that were selected as independent variables, and three types of behavioural responses that were selected as outcome variables. Additionally, the components of FCR (emotions and cognitions) were not examined separately as stipulated by the model, but rather using a single scale. As such, the model in its entirety remains to be empirically examined. What follows is a review and synthesis of this literature using the framework of the cognitive FCR model (Lee-Jones et al., 1997).

Research Supporting the Conceptual Framework: A Synthesis of the Literature

Antecedents

Internal cues. Somatic stimuli are postulated to kindle FCR. Indeed, strong evidence has been found for the relationship between the presence or severity of physical symptoms and FCR. Particularly, robust evidence has emerged for general somatic complaints (Deimling et al., 2006; Liu et al. 2011; Mast, 1998; Matulonis et al., 2008; Mehnert et al., 2004; Mellon & Northouse, 2001; Mellon et al., 2007; Schlairet, 2011), fatigue (Avis et al., 2005; Franssen et al., 2009; Matulonis et al., 2008; van den Beuken-van Everdingen et al., 2008), and pain (Avis et al., 2005; van den Beuken-van Everdingen et al., 2008). While various cancer populations were examined in these studies, women with ovarian cancer experience a wide range of physical symptoms (Wenzel et al., 2002), and appear to evidence a strong association between somatic stimuli and FCR (Matulonis et al., 2008). The relationship between physical symptoms and FCR appears to last long after initial diagnosis and treatment phase (Wenzel et al., 2002). Indeed, Matulonis et al. retrospectively examined quality of life (QOL) in early-stage ovarian cancer survivors who were at least three years or greater from their original diagnosis, and currently free of a cancer recurrence. Findings from this study revealed that the more physical symptoms one experienced, including treatment-related side effects, fatigue, pain, sleep difficulties and abdominal pain, the higher the reported level of FCR. In their study, Custers and colleagues (2017) investigated the internal cues of feeling sick and bodily sensations, and found there was a positive significant relation between these cues and FCR; additionally, both internal cues were significantly and directly associated with body checking in a sample of breast cancer survivors. Finally, feeling sick was significantly and directly associated with seeking professional advice (Custers et al., 2017).

External cues. Several studies have demonstrated an association between the external cues outlined by the cognitive model and FCR. One of the most commonly reported triggers of FCR is follow-up medical appointments or contact with health professionals, such as visits to general practitioners (Lampic, Thurfjell, Bergh, & Sjoden, 2001; Stark & House, 2000) and oncologists (Glynne-Jones, Chait, & Thomas, 1997; Thomas, Glynne-Jones, Chait, & Marks, 1997). For example, long-term breast cancer survivors report highest levels of FCR during critical times of interaction with healthcare providers, such as mammography appointments and visits to the healthcare team. These appointments may coincide with their anniversary of the date they were originally diagnosed with cancer, one of the most significant reminders of breast cancer (Spencer et al., 1999; Vickberg, 2003). For breast cancer survivors who were disease-free, appointments with their doctors or health professionals haves been found to be significantly associated with FCR (Custers et al., 2017). Events like these often trigger thoughts of cancer that are related to the fear of recurrence (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998; Vickberg, 2001). Vickberg (2001) found 75% of her sample (n = 16) identified being around someone else with cancer or who was experiencing a cancer recurrence triggered their own fears of recurrence. Vickberg (2001) also found that 44% of patients reported that being in a situation where a recurrence could be detected, such as a doctor's appointment, triggered their own fear of recurrence. Lampic and colleagues (1994) examined 197 patients with various types of cancer and in different stages of treatment attending routine follow-up visits. Participants completed questionnaires on three occasions: in the waiting room prior to follow-up examination, after the follow-up visit, and three weeks later. Although the majority reported low levels of anxiety, 20% of patients reported moderate or high anxiety that was particularly pronounced before the visit (Lampic et al., 1994). Importantly, the main reason for patient anxiety was the worry about

cancer recurrence, which is consistent with findings from other studies (Cella & Toss, 1986; Northouse, Cacchiolo-Caraway, Pappas, & Appel, 1991).

In ovarian cancer, women with early-stage disease who have completed treatment often evidence high levels of FCR associated with follow-up medical appointments due to repetitive CA125 blood tests, which are used to monitor growth of ovarian cancer (Matulonis et al., 2008). Indeed, in a study comparing quality of life in early and advanced stage ovarian cancer survivors, findings revealed that most survivors were anxious when getting CA-125 testing (early stage 59%; advanced stage 64%), despite being recurrence-free for more than 3 years (Mirabeau et al., 2009).

As posited by the model, other external cues can include chance exposure to reminders about cancer, such as being confronted cancer-related images or information (Custers et al., 2015 and media coverage (Gill et al., 2004). A recent study by Custers and colleagues (2015) investigated whether breast cancer patients with FCR show an attentional bias to cancer-related stimuli using an Emotional Stroop Task with cancer-related words (e.g., "chemo"). The findings revealed that breast cancer patients with FCR showed more interference with cancer words than the healthy controls indicating the role of personal relevance: Patients demonstrated more noticeable color naming interference on cancer-relevant domains (Custers et al., 2015).

The patient's family is another source of potent external cues for FCR. Several studies have documented the interrelationship between the FCR of survivors and their family members (Baider & Kaplan De-Nour, 1988; Mellon, Kershaw, Northouse, & Freeman-Gibb, 2007; Northouse, Mood, Templin, Mellon, & George, 2000; Northouse, Templin, & Mood, 2001). Specifically, in couples, FCR experienced by one partner has been shown to significantly influence the amount of fear experienced by the other. In addition, higher FCR has been linked to both survivors' and caregivers' poorer mental health (Mellon, Kershaw, Northouse, & Freeman-

Gibb, 2007). Family members may trigger FCR through direct probing about the patient's health, which may serve as a reminder of cancer. Alternatively, the avoidance by family members to discuss health or cancer-related topics has also been posited to increase FCR (Lee-Jones et al., 1997). Family members' avoidance of discussions about cancer may be experienced as a lack of social support, which has been associated with higher FCR (Northouse, 1981). For example, in a sample of women with breast cancer, there was a negative association between FCR and the number of significant others with whom women could discuss their breast cancer concerns, and the number of significant others women felt understood their concerns (Northouse, 1981). Furthermore, research has demonstrated that the less family support the patient receives, the greater FCR experienced (Mellon & Northouse, 2001). In Custers et al.'s study (2017), media and social context was included as an external cue in the mediation analyses. It was examined as a single component, comprised of television shows or newspaper articles about cancer or illness, seeing or hearing about someone who is ill, and going to a funeral or reading the obituary section of the newspaper, and was found to be significantly associated with FCR (Custers et al., 2017).

Person's disposition and past coping style. Finally, according to the cognitive model of FCR, a person's disposition and past coping style can serve as an antecedent to FCR. Patients who use avoidance-oriented coping styles or who are less optimistic report more FCR (Deimling, Bowman, Sterns, Wagner, & Kahana, 2006; Stanton, Danoff-Burg, & Huggins, 2002; Stanton et al., 2005). Moreover, greater avoidance/denial coping is positively associated with FCR (Llewelyn et al., 2006; Mehnert et al., 2009; Skaali et al., 2009; Stanton, Danoff-Burg & Huggins, 2002). For example, a cross-sectional study of 1083 breast cancer survivors showed depressive coping styles (including passive behaviour patterns and feelings of helplessness) to be associated with greater fear of cancer progression (Mehnart et al., 2009). Lack of adaptive

coping responses may engender greater FCR, according to the authors of this study. However, it is also possible that FCR, coupled with uncertainty and lack of control, may lead to more depressive coping with disease.

In addition to passive or avoidant coping, moderate evidence has been found for the relationship between FCR and religious coping/spirituality. Two studies (Matulonis et al., 2008; Mirabeau et al. 2009) showed the use of religious/spiritual coping to be significantly associated with lower FCR, and one study (Cannon et al., 2011) identified it as a significant predictor of lower FCR over time. One explanation may be the tendency for religious/spiritual coping to reflect a more acceptance-oriented attitude. Overall, while research supports the relationship between coping strategies and FCR, further investigation is needed to clarify the nature of this relationship.

Components of Fear of Recurrence

Cognitions. According to the FCR model, one's past cancer experience and its treatment are part of the composition of cognitions and interpretations of the threat of recurrence. Previous studies report high rates of intrusive thoughts about cancer—up to 48%—in cancer patients (Bleiker, Pouwer, van der Ploeg, Leer, & Ader, 2000; Mehnert & Koch, 2007). However, few studies have explored to what extent intrusive cognitions were related to cancer, treatment-related events such as cancer disclosure or surgery or to future-oriented fears (Green et al., 1998; Kangas, Henry, & Bryant, 2002; Palmer, Kagee, Coyne, & DeMichele, 2004). Whitaker et al. (2008) investigated the association between intrusive cognitions and anxiety in prostate cancer patients. Intrusive cognitions were reported by 23% of men; of those, 82% of reported intrusions were related to the cancer experience and were significantly associated with anxiety (Whitaker, Brewin, & Watson, 2008). In a sample of women with breast cancer, 37% reported intrusive

thoughts related to their cancer experience and/or treatment (Mehnert et al., 2009). Notably, women who had experienced a recurrence and those who had undergone chemotherapy were found to have significantly higher levels of FCR than those who had not (Mehnert et al., 2009). The consequences of treatment, including physical impairments (e.g., neuropathy, fatigue) were also found to significantly contribute to FCR (Mehnert et al., 2009), highlighting the impact of cancer experience on FCR.

Knowledge about cancer, such as information about cure and survival rates, are also components impacting FCR cognitions. Despite limited data on this issue, findings confirm patient anxiety is reduced by being given clear information about risk of recurrence, on how to recognize signs and symptoms of recurrence, and on the effectiveness of follow-up tests (Bradley, Pitts, Redman, & Calvert, 1999). This type of information also provides reassurance (Bradley et al., 1999), helps with coping (Bradley et al., 1999; Wong & Chow, 2002), and enables involvement (Sahay, Gray & Fitch, 2000; Wong & Chow, 2002). Indeed, a recent systematic review of patients' views of cancer follow-up care revealed that patients primarily want these appointments to alleviate FCR and to receive psychosocial support. Interestingly, evidence suggests that routine hospital follow-up does not lead to early diagnosis of recurrence or improved survival for most types of cancer (Lewis et al., 2009); however, the degree to which patients understand this information is unclear. As patients with high FCR have been found to insist on follow-up medical tests and procedures (Lewis, 2009), patients' understanding of the likelihood of recurrence and the associated signs and symptoms may be an important factor that impacts FCR cognitions.

The model also predicts that one's beliefs about the eradication of the initial cancer will influence one's perception of risk of recurrence. Perceived risk of recurrence is the degree to which survivors believe their cancer will return in their lifetime, and is indicated by the model as

an important component of FCR (Essers et al., 2006; Liu et al., 2011; Tzeng et al., 2010; Waters et al., 2010). The belief in the eradication of the disease is an important determinant of one's perception of risk of recurrence. For example, patients who are more confident that their cancer has been cured are less concerned about recurrence than patients who are less confident (Hall & Fallowfield, 1989; Hartl et al., 2003; Liu et al., 2011).

Emotions. According to the cognitive model, the patients' emotional reactions result from their interpretations and cognitions surrounding the threat of cancer. These fear-based reactions include worry about cancer recurrence and anxiety about cancer (Lee-Jones et al., 1997). In the cognitive model, worry is conceptualized as an emotion; this conceptualization is debatable in the cognitive-behavioural field wherein 'worry' is often considered a cognitive phenomenon (Borkovec, Ray, & Stober, 1998). However, given the goal of the current study, the conceptualization of worry will be consistent with that put forth in the model. According to Lee-Jones' formulation, the construct of worry includes images and emotions of a negative nature accompanied by mental attempts to avoid anticipated potential threat (Borkovec, Robinson, Pruzinski, & DePree, 1983; Lee-Jones et al., 1997). Simard et al. (2010) demonstrated that FCR shares many characteristics with worries seen in Generalized Anxiety Disorder, and becomes more obsessive and uncontrollable as FCR severity increases. Similarly, Whitaker et al. (2009) reported that the majority of patients' intrusive worries were related to cancer (75%), were future-oriented (81%), and were experienced in both image and verbal form.

Additionally, remorse over not opting for more aggressive treatments is another emotion that comprises FCR. Prior research has shown that breast cancer treatment decision-making is largely motivated by the desire to survive and to avoid future recurrences. Moreover, the desire for ''peace of mind'' is a major factor in treatment decision-making (Rosenberg et al., 2013). A

study of prostate cancer survivors found that FCR was a significant determinant of treatment decision regret, and those with diminished concerns about recurrence were less likely to be regretful (Hu et al., 2008). Decision regret appears to be more significant for patients who have experienced a recurrence. For example, women with either a new or recurrent breast cancer are more likely to express some regret about their primary treatment decisions. In a recent study of decision regret following treatment for localized breast cancer, Martinez et al. (2015) administered a decision regret scale at 9 months following diagnosis (time 1) and approximately four years later (time 2). Results demonstrated that women who received a new (i.e., second) breast cancer diagnosis following initial treatment experienced a significant increase in feelings of regret about their treatment decision (Martinez et al., 2015).

Consequences of FCR

Behavioural responses. FCR can lead to dysfunctional behaviours, including excessive body checking, anxious preoccupations, reassurance seeking, and avoidance. Prior research has demonstrated that patients with high FCR report engaging in excessive body scanning and checking for signs or symptoms indicating that the cancer has returned (Lasry & Margolese, 1992). Indeed, cancer survivors who are high in FCR have been described as becoming obsessive over symptoms (Figueiredo, Fries, & Ingram, 2004; Welch-McCaffrey, Hoffman, Leigh, Loescher, & Meyskens, 1989). Self-monitoring of ambiguous symptoms believed to be associated with recurrence often requires repeated reassurance from health care providers during office visits and follow-up (Fredette, 1995). In line with these observations, FCR has been found to be the main reason for patients' anxiety and need for reassurance, and research has demonstrated that the severity of FCR predicted the frequency of reassurance-seeking behaviour (Cannon et al., 2011; Mikkelsen et al., 2009). However, research has also revealed that regular

check-ups with tests and examinations provides only temporary reassurance; and by the time of the patients' next appointment their anxiety has often returned (Allen, 2002; Beaver & Luker, 2005; Bradley et al., 1999; Bradburn et al., 1995; Pennery & Mallet, 2000; Rozmovits, Rose, & Ziebland, 2004), creating the need for continual reassurance. Furthermore, the cognitive model posits that another behavioural response to FCR is limited planning for the future. Indeed, patients who are especially fearful of recurrence have been found to make fewer plans for the future (Hart et al., 2012; Northouse, 1981), although research in this area is limited.

Psychological effects. In addition to serving as a cue to FCR, misinterpretation of physical symptoms can also be an outcome of the activated threat cognitions (Clayton, Mishel, & Belyea, 2006). For example, breast cancer survivors who have arm lymphedema and the associated arm discomfort demonstrate more FCR than those who do not, despite the lack of association between this symptom and recurrence (Liu et al., 2011). The cognitive model also predicts that FCR will result in an increase in somatic anxiety and an increased propensity to panic attacks (Lee-Jones et al., 1997). Indeed, several studies have supported the significant association between anxiety and FCR (Herschbach et al., 2005; Melia et al., 2003; Roth et al., 2009; Shim et al., 2010; Simard & Savard, 2009; Simard et al., 2010; Skaali et al., 2009; van den Beuken-van Everdingen et al., 2008). However, there is no research available that has specifically examined the relationship between panic attacks and FCR.

Limitations of the Current Literature

Despite a considerable proliferation of research in the area of FCR in the past two decades, our understanding of the construct remains limited in several important ways. First, the lack of definitional consensus results in poor operationalization and measurement of the construct, which may help explain the variability in reported prevalence rates FCR and the

inconsistencies in the literature (Crist & Grunfeld, 2012; Koch, Jansen Brenner, & Arndt, 2012; Simard et al., 2013). A recent review of FCR self-report measures revealed that 20 multi-item scales and 7 single-item measures have been used across quantitative studies (Thewes et al., 2012). The substantial heterogeneity in study design, population and FCR assessment tools restrains conclusions that can be drawn. Consequently, researchers have called for future research to confirm the role of potential determinants and consequences of FCR and to evaluate the trajectory of FCR across time (Simard et al., 2013).

A second major shortcoming of the extant literature is how the nature and course of FCR does or does not change over time, as the majority of studies are cross-sectional. The little data that do exist suggest FCR remains stable following diagnosis (Humphris & Rogers, 2004; Llewellyn et al., 2008; Stanton, Danoff-Burg, & Huggins, 2002). For example, longitudinal studies in head and neck cancer patients suggest FCR increases in the seven months after diagnosis (Humphris et al., 2003) and remains unchanged at 12 months (Campbell, Marbella, & Layde, 2000) and at 36 months (Llewellyn, Weinman, McGurk, & Humphris, 2008) post-treatment, respectively. Additionally, a longitudinal study of women with stage I and II breast cancer demonstrated the stability of FCR across three time points, pre-operative (time 1), three months post-operative (time 2) and 12 months post-operative (time 3; Stanton et al., 2002). The stability of FCR has also been supported by cross-sectional research demonstrating that long-term survivors tend to demonstrate comparably elevated levels of FCR several years following diagnosis. For example, a cross-sectional study of breast cancer survivors revealed no significant difference in FCR in patients who ranged from 18 months to 78 months post diagnosis (Mehnart et al., 2009), suggesting that survivors experience similar levels of FCR 6.5 years following diagnosis and treatment as they do 1.5 years after.

Other data conflict with these findings. A longitudinal study of mixed cancers demonstrated that FCR was highest prior to or just following surgery, decreased significantly by two months post-surgery, but stabilized thereafter at 18 months post-treatment (Savard & Ivers, 2013). Furthermore, a study on patients with hematological cancers demonstrated a decline in FCR from pre-treatment to 12 months post-treatment (Sarkar et al., 2014). Although most longitudinal research suggests that FCR is stable over time, recent contradictory findings have highlighted the need for a more in-depth understanding of the trajectory of FCR across time. Recent research suggests that patients with cancer in sites associated with poor prognosis and survival rates are at higher risk to display persistently elevated levels of FCR (Ghazali et al., 2013), suggesting ovarian cancer patients may be at particularly high risk for enduring heightened FCR. This study is the first to our knowledge to prospectively examine the trajectory of theorized components of FCR as well as the associated antecedents and consequences. A greater understanding of not only the stability of FCR itself but of the variables that influence its longitudinal trajectory is important to inform suitable interventions that may prevent FCR from becoming chronic.

Consideration of Alternative Models

The Lee-Jones et al. (1997) cognitive model was chosen to guide the current research because it is the most comprehensive framework available to date. Moreover, it is the only theoretical model developed to understand FCR, whereas other models that have been applied to FCR have been created for other purposes. Another strength of the cognitive model is that it incorporates several of the individual components put forth in the other models. It is important to note that these alternative conceptual models also remain systematically untested, and instead are used inconsistently and loosely as guiding theoretical frameworks, or more often as a theoretical basis to explain findings on a post-hoc basis. A systematic literature search of PsycINFO,

PubMed and Medline was conducted using the search terms *fear of cancer recurrence* and *fear of cancer progression*. This search identified studies published by 2013. At this time, the most commonly cited theoretical models in the literature were the Trade-off hypothesis, the Family Systems Approach, the CSM and the cognitive model. Each of these alternative models is reviewed below.

Trade-off hypothesis

The trade-off hypothesis (Hall & Fallowfield, 1989) was one of the first theoretical frameworks to be applied to FCR. Interestingly, it is the contradictory evidence for this framework that led to the development of Lee-Jones' cognitive model (Lee-Jones et al., 1997). The hypothesis was developed during the 1980's in reaction to the controversy about the preference of mastectomy versus lumpectomy to treat breast cancer. The trade-off hypothesis proposed that although breast preservation (i.e., lumpectomy) may enhance body image, it also increases FCR because only a small part of the breast is excised. Hall and Fallowfield (1989) found mastectomy patients reported feeling more confident that their cancer had been cured and reported less FCR in comparison with other women receiving conservative treatments, such as lumpectomy. However, other studies investigating the trade-off hypothesis have found no difference in FCR between patients who had a mastectomy and those who had undergone a lumpectomy (Beckmann et al., 1983; Lasry et al., 1987). Findings from other studies have even contradicted the trade-off hypothesis, demonstrating that mastectomy patients were more concerned with FCR than those who had undergone lumpectomy (Kemeny et al., 1981). Lasry and Margolese (1982) concluded that in their study that differences in FCR were due to number of surgical interventions, as opposed to surgery type; patients who underwent several operations reported greater FCR. Despite equivocal evidence to support the trade-off hypothesis, this model

highlighted treatment-related factors as being important correlates of FCR that may help explain individual differences. Indeed, the cognitive model acknowledges and incorporates the role that treatment-related factors have on FCR, predicting that past experience of cancer and its treatment, decision regret, and beliefs about the eradication of the initial cancer contribute to FCR (Lee-Jones et al., 1997).

Leventhal's Common Sense Model

Leventhal's Common Sense Model of Illness (CSM; Leventhal et al. 1992) was originally developed in an attempt to understand adherence to medical regimes. The CSM has been used to illustrate why people respond in different ways to the news they have cancer, and why some are more concerned with the possibility of recurrence than others. The development of Lee-Jones et al.'s model was based in part on the CSM, especially the identification and interpretation of internal cues (e.g., physical symptoms) and external cues (e.g., receiving information) that trigger simultaneous cognitive and emotional processes. The CSM referred to the person's representation of the health threat as an "illness representation." The model specifies that when confronted with an illness threat, the cognitive and emotional processing systems act synergistically to influence the way the person responds to the threat. Leventhal and colleagues identified five attributes of illness, identity, time-line, consequences (physical, social or economic), antecedent causes, and potential for cure or control (Leventhal et al., 1980). These attributes are believed to play an important role in determining the strategies the patient uses to cope with the illness threat and select those that they believe to be the most appropriate given their illness representation. Despite often being applied as a guiding framework, there is only partial and contradictory evidence for this model (Crist & Grunfield, 2012).

Family stress-coping framework

This model is a systems framework adapted from McCubbin and McCubbin's resiliency model (1991) to examine possible predictors of FCR for both cancer survivors and their families. According to this model, the family's ability to adapt depends on personal factors, such as demographics, the number of stressors the family is facing (both illness-related and family stressors), and the family's resources, such as social support. These antecedent factors are suggested to impact the family's appraisal of their situation or the meaning of the cancer illness, which in turn impacts FCR. Importantly, the relationship between FCR experienced by the family member and that experienced by the patient is believed to be reciprocal. Several studies have documented the mutual influence that patients and family members have on each other's adjustment and quality of life (Baider & Kaplan De Nour, 1988; Mellon, Kershaw, Northouse, & Freeman-Gibb, 2007; Northouse, Mood, Templin & Mellon, 2000; Northouse, Templin, & Mood, 2001). The cognitive model incorporates the impact of family of FCR by including family concerns as an important component of the model (Lee-Jones et al., 1997).

Taken together, the cognitive model of FCR (Lee-Jones et al., 1997) was selected to guide the current research due to its comprehensive nature and incorporation of many of the key elements of other suggested models. Furthermore, the extant research supports the investigation of the model components in a more thorough and systematic fashion. The breakdown and identification of the specific components that comprise FCR addresses the lack of definitional consensus in the literature. An empirically supported definition of the construct is necessary to stimulate and standardize the research and clinical activity in this area (Simard et al., 2013). Outlining key psychosocial antecedents is critical for understanding how FCR is triggered, and the confirmation of the role of these potential antecedents is necessary for the development of preventative strategies. The conceptualization of

consequences as involving behavioural responses and psychological effects is also helpful for treatment development. Toward this end, the fact that the cognitive model is grounded in cognitive-behavioural theory makes it amenable to well-established intervention strategies. Therefore, the evaluation of this comprehensive model is a priority for the field to progress.

Ovarian Cancer

Given the extremely high rates of recurrence in ovarian cancer, FCR is particularly relevant for this population. Patients with early-stage disease have approximately a 30–40% risk of recurrence (Young et al., 1990), while more than 70% of patients with advanced ovarian cancer will experience disease recurrence (Romero & Bast, 2012). Despite these significant rates, ovarian cancer has largely been overlooked in the FCR research, which significantly limits our understanding of this particularly vulnerable population.

Ovarian cancer is the fifth most common cancer worldwide and the seventh most common cause of deaths from cancer in women, with 225,500 new cases and 140,200 estimated deaths worldwide (Jemel, Bray, Center, Ferlay, & Forman, 2011). Indeed, it is estimated that this year, 2,800 Canadian women will be newly diagnosed with this disease (Canadian Cancer Statistics, 2017). Ovarian cancer has long been referred to as the "silent killer" since disease is often not detected until it is at an advanced stage (Sun, Ramirez, & Bodurka, 2007). Overall survival is relatively poor in women diagnosed with ovarian cancer, with a 5-year survival rate of approximately 45% (Romero & Bast, 2012). Despite intensive research efforts over the past decade directed toward improved detection and treatment of ovarian cancer, the majority of women diagnosed with ovarian cancer succumb to the disease. Although combinations of drugs can prolong survival, recurrent disease is not curable (Romero & Bast, 2012).

The poor detection of ovarian cancer contributes to an even greater sense of vulnerability (Hall & Rustin, 2011). Although the majority of women report experiencing symptoms before diagnosis (Sun, Ramirez, & Badurka, 2007), common symptoms such as early satiety, bloating, and abdominal pressure or fullness are often initially mistaken for other gastrointestinal issues, such as irritable bowel syndrome, colitis, or diverticulitis (Goff et al., 2000; Sun et al., 2007).

Additionally, no effective screening tool or combination of screening tools exists for ovarian cancer. Although many clinicians recommend serial transvaginal ultrasounds and assessment of serum CA-125 levels for women at highest risk, screening is not always effective and is not routinely offered to women who are not at increased risk (Han, Zou, & Fang, 2017). Given the combination of the staggering rate of recurrence and bleak associated prognosis, as well as the lack of effective screening, women with ovarian cancer represent a unique and important population within which to investigate FCR.

Overview of the Present Study

The present study addressed the limitations of the existing literature by testing the cognitive model of FCR proposed by Lee-Jones and colleagues (1997) within an ovarian cancer population. Additionally, the stability of FCR was examined by evaluating the model in a two-wave self-report study. Patients completed assessment measures at baseline (Time 1) and three months post-baseline (Time 2).

Aims and Hypotheses

Aim 1: To test the cognitive model of FCR (Lee-Jones et al., 1997) in an ovarian cancer sample. It was hypothesized that our data would support the model (refer to Figure 1). We expected to see each component of the model supported by the latent variables (e.g., internal and external cues would be associated with thoughts and emotions as outlined by the model, which would in turn be associated with the consequences put forth by the model, namely behavioural responses and psychological effects).

Aim 2: To examine the stability of the cognitive model of FCR (Lee-Jones et al., 1997) at each time point. It was hypothesized that the components of the model would be equivalent at Time 1 (baseline) and Time 2 (three months post-baseline).

Aim 3: To test the predictive validity of the model. It was expected that FCR at baseline would predict consequences at Time 2.

Methods

Participants

Participants were ovarian cancer patients receiving care in the medical oncology, radiation, and surgical oncology clinics at the Princess Margaret Hospital in Toronto, ON. Patient medical records were screened for eligibility criteria, which were then confirmed with medical staff in clinic.

Eligibility criteria included: (1) having received a diagnosis of invasive ovarian cancer; (2) ability to speak and read English; (3) being over the age of 18; (4) capable of providing informed consent (5) permission granted by a healthcare member to approach the patient. Patients who were diagnosed with a noninvasive tumor were excluded.

Procedure

Once the eligibility criteria were confirmed with medical staff, patients were approached during their clinic appointments. The physician or other member of the patient's circle of care team received permission from the patient to invite the research staff into the room. Research staff then provided a brief introduction to the study, and if time permitted, verbal consent was obtained. If the participant was interested but unable to provide consent in the clinic, study staff obtained the patient's contact information and completed verbal consent over the phone.

To obtain consent, research staff provided a verbal description of the study overview, procedure, and expected time commitment, according to a script. Patients were invited to ask questions or request clarification as needed. The individual who obtained consent requested that the participant verbally explain their understanding of their participation in the study. If the participant incorrectly explained some aspect of their participation or the purpose of the study, the person obtaining consent clarified any misunderstandings. Patients recruited in clinic were given an information letter and copy of the written consent form for their own records. Patients who were consented over the phone received these documents in the mail, according to preference.

After providing informed consent, patients were assigned a study ID to protect confidentiality. Patients were given the option to complete an online or paper-copy version of the questionnaire. For the online questionnaire, patients were emailed a link to a web-address where they completed the online questionnaires and were given their study ID number to enter into the survey. At any time during the web-based survey, patients could stop participating in the survey by selecting an "opt-out" option or refusing to answer any of the items. Patients could also save their survey and return to it at a later time using their study ID number. Patients who did not have access to the internet or who did not wish to complete the survey online were mailed a hard-copy version of the web-based questionnaires with their assigned study ID number, along with a pre-stamped return envelope. Upon completion of the Time 1 survey, patients were mailed a $20 gift card as a token of appreciation for their time.

Three months following completion of their baseline assessment, study staff emailed patients their study ID and a link to the web-address where they completed a follow-up assessment. If patients had previously requested a hard-copy version of the questionnaire, study staff mailed the paper copy of the follow-up assessment and a pre-stamped return envelope. The

follow-up survey took approximately 45 minutes to complete. Upon completion of the Time 2 survey, patients were mailed a $15 gift card as a token of appreciation for their time.

Measures

In this section, the Fear of Cancer Recurrence Inventory (FCRI; Simard & Savard, 2009) is first reported because five of the FCRI subscales are used, but they fit into the cognitive model of FCR in various ways. Next, the additional measures used to examine the specific components of the cognitive model of FCR will be presented, organized by antecedents, components of FCR and consequences.

Fear of Recurrence Inventory. (FCRI; Simard & Savard, 2009). The FCRI is a relatively new measure of FCR, measuring some aspects of cognitions and emotions, as specified by the model, as well as antecedents and consequences. The FCRI is comprised of 42 items evaluating seven specific components of FCR. These subscales include: triggers, severity, psychological distress, functioning impairments, insight, reassurance and coping strategies. Research has supported the internal consistency ($\alpha = 0.95$) and the temporal stability ($r = 0.89$) of the FCRI, as well as its construct validity with other self-report scales assessing fear of cancer recurrence ($r =$ 0.68 to 0.77; Simard & Savard, 2009). For the purposes of this study, five of the seven subscales map directly onto the cognitive model of FCR, specifically the triggers, severity, psychological distress, and reassurance and coping strategies subscales. The reliability of each of these subscales has been found to be excellent (Simard & Savard, 2009): triggers ($\alpha = 0.90$), severity ($\alpha = 0.89$), psychological distress ($\alpha = 0.86$), reassurance strategies ($\alpha = 0.75$), coping strategies ($\alpha = 0.89$). In terms of convergent validity, strong correlations have been found between the FCRI total score and the Concerns About Recurrence Scale (CARS; Vickberg, 2003) overall fear subscale score, $r(599) = 0.77$, $p < .001$; the CARS nature of the fear subscale score, $r(599) = 0.74$, $p < .001$; the

Fear of Recurrence Questionnaire (FQR; Northouse, 1981) total score, $r(599) = 0.71$, $p < .001$; and the Illness Worry Scale (IWS; Robbins & Kirmayer, 1996) total score, $r(599) = 0.68$, $p < .001$. With regards to divergent validity, low to moderate correlations have been found between the FCRI total score and constructs assessed by the Quality of Life Questionnaire (QLQ; Aaronson et al., 1993) that are not believed to be directly associated with FCR, such as physical functioning, $r(599) = -0.22$, $p < .001$, role functioning, $r(599) = -0.31$, $p < .001$; cognitive functioning, $r(599) = -0.20$, $p < .001$; social functioning, $r(599) = -0.35$, $p < .001$; and global quality of life, $r\ (599) = -0.36$, $p < .001$ In terms of discriminant validity, higher FCRI total score was significantly associated with younger age, $r(599) = -0.31$, $p < .001$; and with female gender, $r(599) = 0.31$, $p < .001$. However, there was no significant association with education level, $r(599) = 0.06$, $p = 0.21$. Additionally, a significantly higher FCRI total score was found in patients who had received chemotherapy, $r(599) = 0.26$, $p < .001$; radiotherapy, $r(599) = 0.12$, $p = .005$; and surgery, $r(599) = 0.10$, $p = .011$; and in patients who had had a localized, $r(599) = 0.12$, $p = .003$; or metastatic cancer progression, $r(599) = 0.14$, $p = .001$. On the other hand, no significant association was found with the time elapsed since the cancer diagnosis, $r(599) = -0.001$, $p = .99$. The FCRI severity subscale has demonstrated a strong correlation with the total FCRI score ($r = .84$), and has been shown to reliably identify the presence of clinically significant levels of FCR, using a cut-off score of 13 (Simard & Savard, 2015).

Under antecedents, external cues, specifically exposure to cancer cues, was measured with the triggers subscale. For example, respondents were asked to indicate how often certain situations make them think about the possibility of cancer recurrence on a scale from 0 (*never*) to 4 (*all the time*). Examples of situations include television shows or newspapers articles about cancer or illness, medical appointments, and feeling physically unwell. In terms of the

components of FCR, the following cognitions were measured by the severity subscale: "beliefs about eradication of initial cancer" and "perception of personal risk." Patients' beliefs about the eradication of their cancer was assessed using a single item: Patients were asked to rate how much "[they] believe that [their] cancer is cured and will not come back" on a scale from 0 (*not at all)* to 4 (*a great deal).* To assess perceived risk of recurrence, patients were asked "in your opinion, are you at risk of having a cancer recurrence?" on a scale ranging from 0 (*not at all at risk)* to 4 (*a great deal at risk*). The 4-item psychological distress subscale was used as a singular scale to assess the emotion component worry about cancer recurrence. Specifically, patients were asked "when I think about the possibility of cancer recurrence I feel": 'Worry, fear or anxiety,' 'Sadness, discouragement or disappointment,' 'Frustration, anger or outrage,' 'Helplessness or resignation'. Answer options range from 0 (*not at all*) to 4 (*all the time*). In terms of consequences, the reassurance and coping strategies subscales were used to assess the "body checking" and "seeking advice" components of the behavioural responses suggested by the cognitive model of FCR. Respondents were asked to answer the statement "When I think about the possibility of cancer recurrence, I use the following strategies to reassure myself." Item examples include "I examine myself to see if I have any physical signs of cancer (body checking) and "I call my doctor or other health professional" and "I talk to someone about it" (seeking advice). Answer options range from 0 (*never)* to 4 (*all the time*).

The following additional measures were used to assess each component of the cognitive model of FCR. The internal consistency within cancer populations in prior research has been provided for measures, when available.

Antecedents.

The Illness Perception Questionnaire- Revised. (IPQ-R; Moss-Morris et al., 2002). The IPQ-R is a 38-item scale widely used to assess the five components of the illness representation – identity, consequences, timeline, control/cure and cause in Leventhal's Self-Regulatory Model (Leventhal et al., 1984, 1997). This measure was used to assess Somatic Stimuli and Interpretation of Symptoms. First, the IPQ-R asks patients to rate whether or not they have experienced a symptom since their illness using a yes/no response format. Next, patients indicate whether or not they believe the symptom to be specifically related to their illness. The sum of the "yes-rated" items on this second rating comprises the illness identity subscale. Items are rated on a 5-point Likert type scale, ranging from *strongly disagree* to *strongly agree*. The IPQ-R has been used in studies of illness adaptation in patients with a wide range of conditions, including breast cancer (Adachi, Toyoda, Kitamura, & Ueno, 2015). The Cronbach's alpha coefficients for the scales in a breast cancer population ranged from .70 to .89 (Adachi, Toyoda, Kitamura, & Ueno, 2015). Data from renal dialysis inpatients has been used to examine the test–retest reliability of the IPQ-R over a three-week period (Moss-Morris et al., 2002). The dimensions of IPQ-R generally showed good stability over this period with correlations ranging from .46 to .88. Personal control was the only dimension to show a correlation less than .5. Attributional and identity beliefs appear to remain the most consistent over this time period. Additionally, the six-month retest reliability of the IPQ-R was investigated within a rheumatoid arthritis sample with the results confirming acceptable consistency over this time period. Except for cyclical timeline all the correlations between the two time points were greater than .5. Once again the attributional beliefs appeared to be most temporally consistent, as did patients' emotional representations.

The Positive and Negative Affect Schedule (PANAS; Watson et al., 1988) has been used to determine the discriminant validity of the IPQ-R. The positive affect (PA) scale measures the degree to which a person feels enthusiastic, active, and alert, while the negative affect (NA) dimension assesses subjective distress and discomfort. Pearson's correlations were found to be generally small to moderate in size. The most significant association was between emotional representations and NA (r = .54) suggesting that trait NA accounts for around 29% of the variance in the emotional upset generated by the illness. NA also demonstrated positive associations with a strong illness identity, chronic and cyclical timeline, beliefs in serious consequences, and psychological, risk factor, and immune attributions. These correlations ranged between .17 and .35. Personal and treatment control beliefs and chance attributions were unrelated to NA. Control beliefs did show, however, a small positive association with trait PA. PA was also negatively associated with emotional representations, illness coherence, illness identity, and chronic timeline with r's ranging from -.19 to -.26. PA was unrelated to any of the attributional beliefs or cyclical timeline.

Openness to Discuss Cancer in the Nuclear Family. (ODCF; Mesters et al., 1997). This nine-item scale assesses open discussion of problems related to cancer in the family (e.g., "I talk as little as possible about my illness because I don't want to make my family uneasy"). Patients were asked to select from four answer options, ranging from 1 (*strongly agree)* to 4 (*strongly disagree*). The scale scores were computed by summing the items. Research has found good internal consistency for the measure (α = 0.86; Mesters et al., 1997). Test-retest reliability for the ODCF has been examined in a longitudinal study of head and neck cancer patients (Mesters et al., 1997). Patients in this study (N = 133) were prospectively examined from the time just before their first treatment (measurement one) to 6 weeks (measurement two), 13 weeks (measurement

three), and 52 weeks after treatment (measurement four). Test-retest correlations were calculated to check the instrument's stability over time, and the findings revealed that, in general, the openness of discussion scale measures a feature that appears to be fairly stable over time. Correlations between measurements one and two, one and three, and one and four were all above .59 (r = .62, p < .01*;* r = .60, p < .01 and r = .59, p < .01, respectively). Test-retest correlations between measurement points two and three and two and four were r = .66, p < .01 and r = .58, p < .01, respectively). The highest correlation was found between measurements three and four, r = .70, p < .01. No additional information regarding the psychometric properties is available to our knowledge. This measure was used to assess family contact in the current study.

***The Brief COPE*.** (Carver, Scheier, & Weintraub, 1989). The Brief COPE is a validated, multidimensional coping inventory used to assess situational coping. The short form version (28 items) of the COPE assesses both adaptive and maladaptive coping strategies (e.g., "I've been getting emotional support from others"). Higher scores indicate more frequent use of a particular coping strategy as response options range from 0 (*I haven't been doing this at all*) to 3 (*I've been doing this a lot*). The Brief COPE has been used with cancer populations, and each scale has demonstrated adequate internal reliability, with Cronbach's alpha on the scales ranging from .78 to .94 (Grande, Arnott, Brundle, & Pilling, 2014). Convergent validity has been established using the Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock & Erbaugh, 1961), the Beck Anxiety Inventory (BAI; Beck, Epstein, Brown, & Steer, 1988), the Connor Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003), and the Short Form-36 Health Survey (SF-36; Ware & Sherbourne, 1992). Generally, the correlations showed moderate effect sizes (Cohen, 1988). Divergent validity was evidenced through the non-significant association between coping factors and Wecshler Abbreviated Scale of Intelligence vocabulary (WASI; Steer, Ranieri, Beck,

& Clark, 1993). Given that coping factors and cognitive reasoning had no theoretical basis to be related, the latter was suitable to test the discriminant validity of the proposed scale (Campbell & Fiske, 1959). For the current study, the adaptive coping strategies were used to assess past coping in the model. A higher score reflected more use of positive coping strategies.

The Life Orientation Test–Revised. (LOT-R; Scheier, Carver, & Bridges. 1994). This 10-item measure assesses generalized dispositional optimism (e.g., "In uncertain times, I usually expect the best") and pessimism (e.g., "I rarely count on good things happening to me"), and was used to assess Predisposition in the current study. Patients were asked to select the answer option that best corresponds to how they feel, ranging from 0 (*I agree a lot*) to 4 (*I disagree a lot*). On a 5-point Likert scale, response categories ranged from 0 (*strongly agree*) to 4 (*strongly disagree*). The optimism and pessimism subscales are scored by summing the corresponding items. A total score can be calculated, adding the optimism and the inverted pessimism score. Response scores range from 6 to 30, whereby higher values indicate higher levels of optimism. The LOT-R has been used in research with cancer populations and has demonstrated good reliability, with a Cronbach's alpha of .80 (Mazanec, Daly, Douglas, & Wilson, 2010). Correlations with health-related variables have been examined to determine convergent validity (Glaesmer et al., 2011). Pearson's correlations were computed between the subscales and total score of the LOT-R and depression and anxiety (Patient Health Questionnaire; Loewe, Spitzer, Zipfel, & Herzog, 2002), pain disability (Pain Disability Index; Dillman, Nilges, Saile, & Gerbershagen, 1994), and posttraumatic symptomatology (Post-Traumatic Diagnostic Scale; Foa, Cashman, Jaycox, & Perry, 1997; Griesel, Wessa, & Flor, 2006). Optimism was more strongly correlated than pessimism for all the scales and the total LOT-R score was significantly correlated with

depression (r = -.32, p < .001), anxiety (r = -.22, p < .001), pain disability (r = -.31, p < .001), and posttraumatic symptomatology (r = -.18, p < .001).

Components of Fear of Recurrence.

Past experience with cancer. Medical information, including stage, time since diagnosis, type of treatment, and number of previous cancer diagnoses (including recurrences) was obtained from medical chart review. Past cancer experience was measured by tallying how many cancer diagnoses each patient had received.

Knowledge base. Perceived knowledge about ovarian cancer and its treatment was assessed with a five-item measure created for this study in consultation with the co-principal investigator, who is a gynaecological surgical oncologist at the Princess Margaret Hospital. Patients were asked to rate the extent to which they feel knowledgeable about various aspects of their ovarian cancer experience and treatment. Example items from this measure include "How knowledgeable do you feel about ovarian cancer?" and "How knowledgeable do you feel about the likely course of your ovarian cancer (for example, your prognosis or the likelihood that it will progress)?" Answer options include *very knowledgeable, somewhat knowledgeable, not very knowledgeable, not knowledgeable at all.* Higher scores reflected less perceived knowledge.

Breast Cancer Fear Scale (Champion et al., 2004). The breast cancer fear scale is a measure that assesses cancer-related fear. For the current study, the wording was altered to ask about cancer in general (e.g., "How do you feel when you think about cancer?"). This measure was used to assess anxiety about cancer. The scale has demonstrated excellent item-total correlation with an overall alpha of .91 (Champion et al., 2004). The scale has also been adapted and used with colorectal cancer patients (Leung, Wong, & Chan, 2014). In this sample Cronbach's alpha for the scale was .94, suggesting good internal consistency. Test-retest

reliability coefficient over a one-month interval was 0.52, $p < .001$, which is considered as moderate according to Cronk's criterion (2004), indicating an acceptable stability in the scale.

Decision Regret Scale. (Brehault et al., 2003). The Decision Regret Scale is a five-item measure that assesses regret after health care treatment decisions. Patients are asked to reflect on the first decision they made about their cancer treatment, and rate the extent to which they agree with each statement on a Likert scale from 1 (*strongly agree*) to 5 (*strongly disagree*). Example items include "I regret the choice that was made" and "I would go for the same choice if I had to do it over again." The scale has demonstrated good internal consistency ($\alpha = .81$; Hickman, Pinto, Lee, & Daly, 2012). The decision regret scale has been evaluated in the context of four different studies. The first study population was menopausal women deciding whether or not to have hormone replacement therapy (HRT), who completed the scale 9 months after making their decisions. The second study population was women with breast cancer deciding whether or not to proceed with adjuvant therapy after the primary surgical intervention. These women completed the measure 3 months after the decision about breast cancer adjuvant therapy (BCAT). The third study population was a sample of women deciding on breast cancer surgery, specifically between lumpectomy and mastectomy (BCS), who completed the measure three years after making their decision. Lastly, the fourth study population was a sample of men considering different treatment options for prostate cancer (PCT), completing the measure three months after making their treatment decision. Internal consistency was high across all four groups; α was .92 for the HRT decision, .84 for the BCAT group, .86 for the BCS group, and .81 for the PCT group. Item-total correlations ranged from 0.62 to 0.89 for the HRT group, from .50 to .72 for the BCAT group, from 0.61 to 0.79 for the BCS group, and from .50 to .67 for the PCT group. To our knowledge,

there is no additional psychometric information available for this measure. This scale was used to measure treatment decision regret in the current study.

Consequences

Future-Oriented Planning Scale. (Prenda & Lackman, 2001). This five-item scale measures self-reported future oriented planning style of life management (e.g., "I live one day at a time," and "I like to make plans for the future"). These items are based on a 4-point Likert scale format, with response options ranging from *a lot* to *not at all*. Patients were asked to indicate how much each item described them. The psychometric properties of this scale have yet to be established. This scale was used to assess limited planning for the future.

The Short Health Anxiety Inventory. (SHAI; Salkovskis, Rimes, Warwick, & Clark, 2002). The SHAI is a validated self-report measure designed to assess the full continuum of health anxiety, ranging from low health anxiety to hypochondriasis. The SHAI contains 18 items that assess health anxiety independently of physical health status. Items assess worry about health, awareness of bodily sensations or changes, and feared consequences of having an illness (Salkovskis et al., 2002). Each question consists of a group of four statements, and patients were asked to select which statement best describes their feelings over the past six months. An example of a group of statements is: (a) If I have a bodily sensation or change I rarely wonder what it means (b) If I have a bodily sensation or change I often wonder what it means (c) If I have a bodily sensation or change I always wonder what it means (d) If I have a bodily sensation or change I must know what it means. The scale has demonstrated adequate test-retest reliability ($\alpha = 0.81$; Salkovskis, Rimes, Warwick, & Clark, 2002). Showing evidence of good convergent validity, the SHAI has been found to be strongly correlated with another measure of the same construct, the Illness Attitude Scale ($r = .63$, $p < .01$). The SHAI has also evidenced divergent validity as it has been most weakly correlated with the Social Interaction Anxiety

Scale $r = .31$, $p < .01$). The current study used two items from the SHAI that assessed one's reaction to a bodily sensation or change, and one's reaction to an unexplained bodily sensation.

***State-Trait Anxiety Inventory*.** (STAI; Spielberger, 1983). The STAI is a validated 20-item measure which includes separate measures of state and trait anxiety. Various reliability and validity tests have been conducted on the STAI and have provided sufficient evidence that the STAI is an appropriate and adequate measure for studying anxiety in research and clinical settings (Sesti, 2000). The scale has been evaluated in women with early stage breast cancer, demonstrating an internal consistency alpha coefficient of .90 (De Vries & Van Heck, 2013), and re-test reliability (average $r = .88$, Barnes, Harp, & Jung, 2002). Only the trait-anxiety scale was used in the current study to assess Increase in Somatic Anxiety. The stability of the trait-anxiety scale has been assessed on a sample of high school students for test-retest intervals ranging from .65 to .86 (Spielberger, 1980). The convergent validity of the trait subscale has been assessed in a sample of university students, with results demonstrating that scores on the trait version of the STAI were strongly positively correlated with scores on the trait version of the State Trait Inventory for Cognitive and Somatic Anxiety (STICSA) and the anxious symptoms subscale of the Mood and Anxiety Symptom Questionnaire (MASQ; $rs \geq .58$; Roberts, Hart, & Eastwood, 2016).

***Panic Disorder Severity Scale*.** (PDSS; Shear et al., 2001). The PDSS is a seven-item instrument used to assess the frequency of panic attacks and the overall severity of panic disorder symptoms. The PDSS has demonstrated acceptable internal consistency ($\alpha = .65$). The PDSS has demonstrated sound psychometric properties. In a sample of patients with primary panic disorder (PD) and mild or no agoraphobia, the PDSS was shown to have acceptable internal consistency (Cronbach's $\alpha = .65$), high interrater reliability with intraclass correlation coefficients ranging from .87 to .88, and high convergent validity with a number of anxiety-related measures (Shear

et al., 1997). In a follow-up study of the measure in a sample of individuals with and without PD, the PDSS demonstrated good internal consistency (Cronbach's $\alpha = .88$) and test–retest reliability ($r = .71$), with individuals with PD scoring higher on the measure than those without (Shear et al., 2001). Furthermore, multiple studies have documented that the PDSS is sensitive to change with treatment (see, e.g., Otto, Pollack, Penava, & Zucker, 1999; Pollack, Otto, Worthington, Manfro, & Wolkow, 1998; Shear et al., 1997). In the current study, this scale was used to assess Increased Propensity to Panic Attacks.

Statistical Analyses

The analyses involved a 3-step approach: (1) examining measurement models; (2) specifying structural models; (3) comparing models.

Aim 1: To test the cognitive model of FCR (Lee-Jones et al., 1997) in an ovarian cancer population.

Examining measurement models. The first step was to test the measurement model, represented in Figure 2. There is debate over the use of confirmatory factor analysis (CFA) and exploratory factor analysis (EFA) with many researchers asserting that CFA is overapplied and used inappropriately, as a significant amount of evidence is required as a foundation for an analysis to be described as confirmatory. Despite the theoretical basis of the model being tested, the present study is largely exploratory in nature. Importantly, as this is the first study to test the cognitive model of FCR, the scales used to measure the proposed latent constructs and the relationship amongst these constructs have yet to be tested. Indeed, Lee-Jones et al. (1997) offer little specification of the relationship amongst constructs. Given the largely exploratory nature of this study, an EFA was conducted to determine the factor structure.

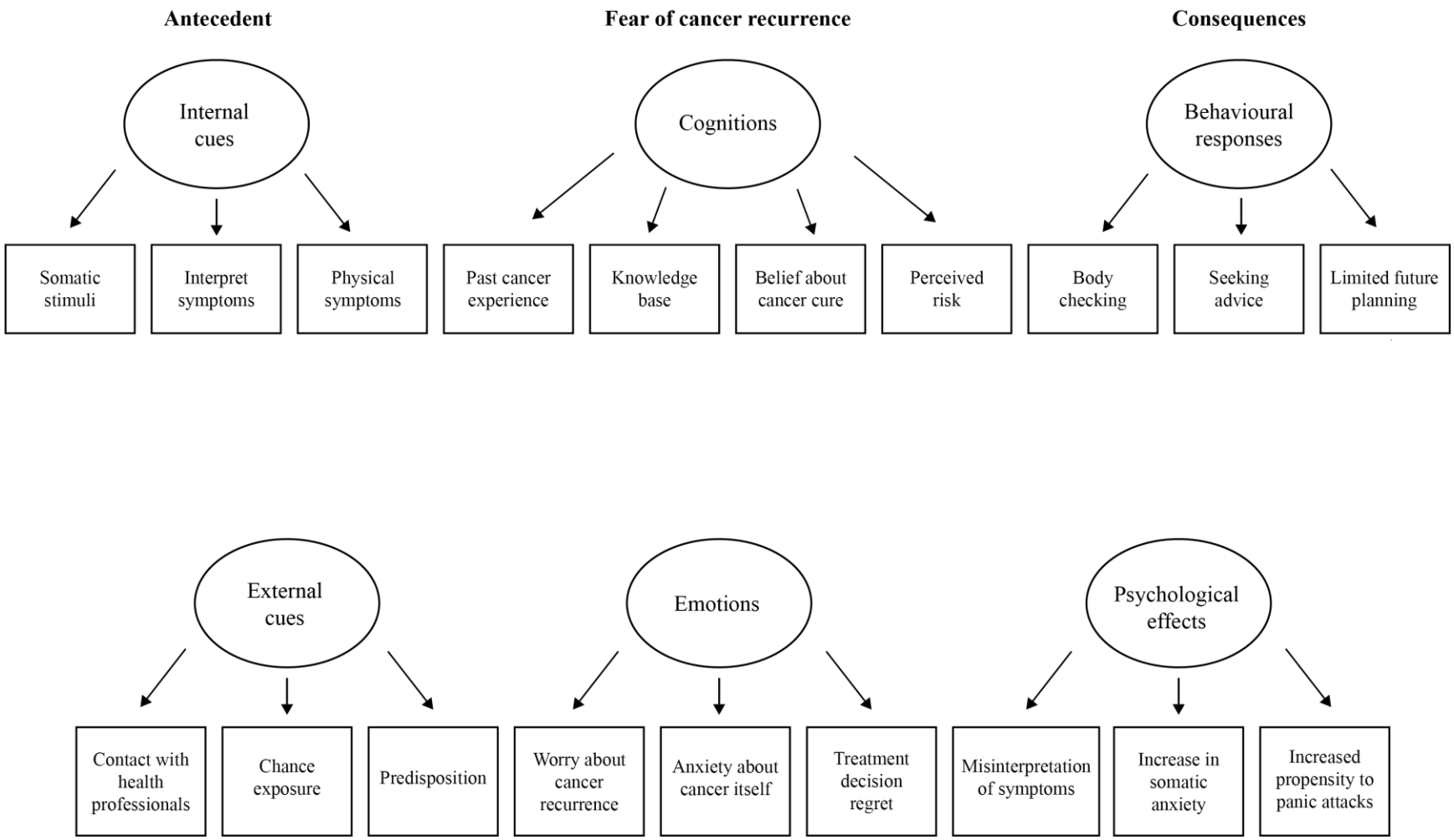

Figure 2. The measurement model

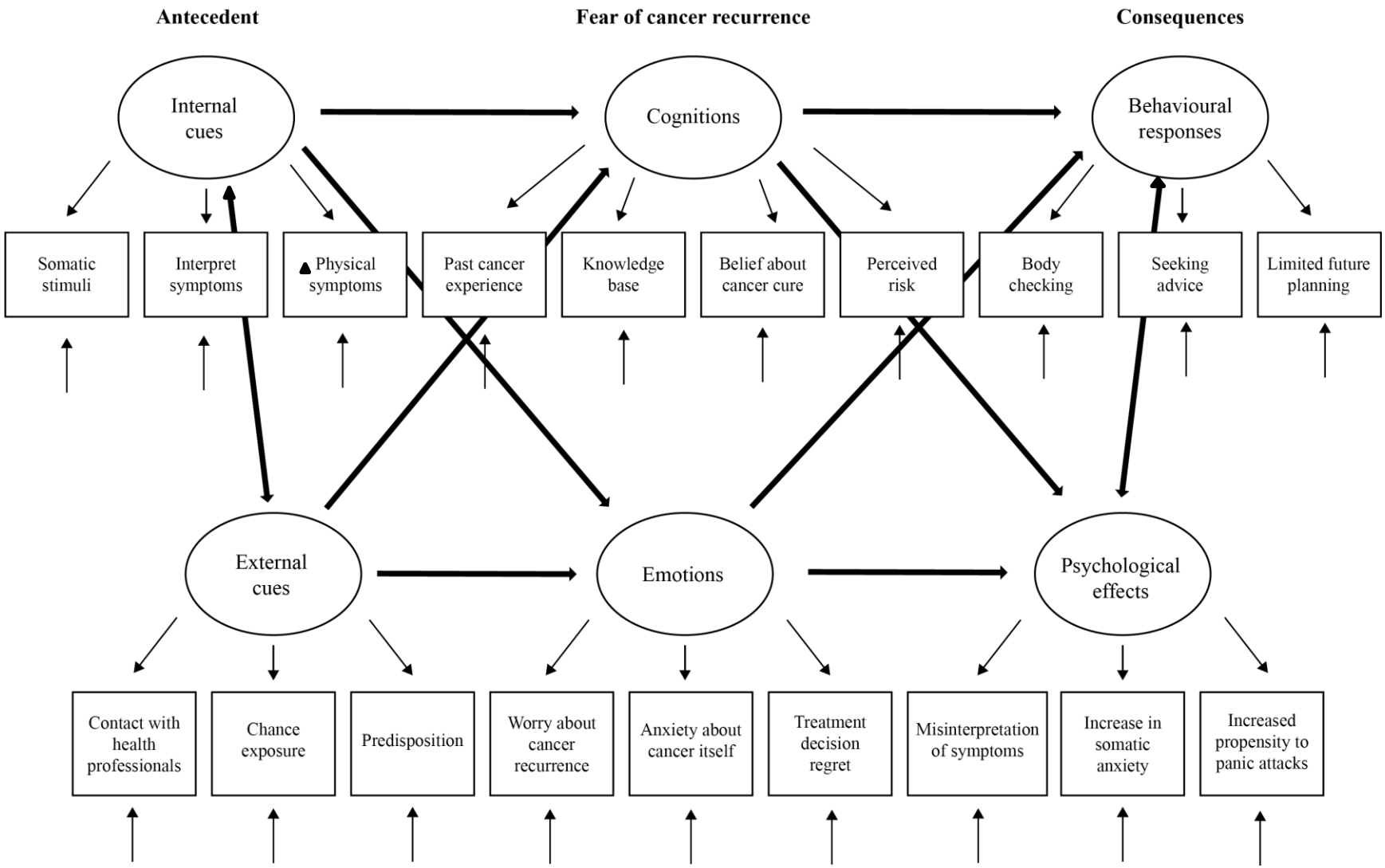

Figure 3. The structural model with indicators. *Note*. The small arrows pointing to the indicators represent error terms

Specifying structural models. To address Aim 1, we tested the structural model for Model 1 (see Figure 3) using structural equation modeling (SEM). SEM is a statistical procedure to evaluate how latent constructs, each represented by manifest indicators, relate to one another and how they form a multivariate model. Latent variables are variables that are not directly observed but are rather inferred from other variables that are observed (directly measured). A manifest variable is a variable that can be directly measured or observed. The SEM models were estimated using maximum ML and full-information maximum likelihood (FIML) estimation of missing data (e.g., see Enders & Bandalos, 2001) using the lavaan package. One assumption of ML is that there is multivariate normal distribution of the data. While deviations from normality from univariate distributions can help assess with model diagnostics, it is not an assumption for CFA; but normality on the full set of variables (n = 19) is a statistical assumption. Multivariate normality was assessed using Mardia's multivariate normality test (Mardia, 1980). To assess model fit, both the traditional χ^2 and Wheaton and colleagues' (1977) relative/normed chi-square (χ^2 / df) were used. The χ^2 / df often used alongside the traditional χ^2, as it minimizes the impact of sample size on the model (Hu & Bentler, 1999). Although there is no consensus regarding acceptable ratio for this statistic, less than 2 is considered acceptable (Tabachnick & Fidell, 2007). Three other fit indices were utilized. First, the Comparative Fit Index (CFI), which assumes that all latent variables are uncorrelated (null/independence model) and compares the sample covariance matrix with this null model. CFI ranges from 0 to 1 with a larger value indicating better model fit. Acceptable model fit is indicated by a CFI value of 0.95 or greater (Hu & Bentler, 1999). Second, the Root Mean Square Error of Approximation (RMSEA) was used. The RMSEA is related to residual in the model, and tests how "badly" the model fits (Byrne, 1998). RMSEA values range from 0 to 1 with a smaller RMSEA value indicating better

model fit. An RMSEA below .08 indicates acceptable fit, and values between .08 and .10 indicate mediocre fit (MacCallum, Browne, & Sugawara, 1996). Finally, the Standardized Root Mean Square Residual (SRMR) was used, which is an absolute measure of fit and is defined as the standard difference between the observed correlation and the predicted correlation. Values for the SRMR range from zero to 1.0 with a smaller SRMR value indicating better model fit. Values less than .05 (Byrne 1998; Diamantopoulos, & Siguaw, 2000) indicate a well-fitting model, however values as high as .08 are deemed acceptable (Hu & Bentler, 1999). Overall model fit was established using a relative fit index, specifically the CFI, in combination with the SRMR and the RMSEA, as recommended (Hu & Bentler, 1999; Hooper, Couglan & Mullen, 2008).Modification indices were examined to see how fit of the model could be improved (e.g., allowing errors to be correlated). SEM was also used to test the relationships between antecedents, FCR and the consequences. Given that the cognitive model does not posit a direction for the relationship between the components of FCR, there was no theoretical reason to include a regression path between these components. The cognitive model does suggest that the components are associated; therefore the emotional experience and the appraisals of cancer prognosis were included as covariances in the model.

Parameter estimates were examined to evaluate the relative contribution of each indicator to the factor. The interpretation of the parameter estimates is similar to the interpretation of a regression. Unstandardized estimates represent that for a one-raw-unit increment on a predictor, the outcome variable increases (or if B is negative, decreases) by a number of its raw units corresponding to what the B coefficient is. Standardized relationships represent that for a one-standard deviation increment on a predictor, the outcome variable increases (or decreases) by some number of standard deviations corresponding to the β coefficient. Within the same

regression equation, the different predictor variables' unstandardized B coefficients are not directly comparable to each other, because in this study, the raw units for each scale are different. On the other hand, with standardized analyses, all variables have been converted to a common metric, namely standard-deviation (*z*-score) units, so the β coefficients can meaningfully be compared in magnitude. In this case, whichever indicator variable has the largest β (in absolute value) can be said to have the most potent relationship to the latent variable. For example, results show that the indicator worry cancer recurrence has the highest loading on the latent variable emotional experience, meaning that it accounts for more variance than the other indicators, although does not test if they are significantly different from one another.

Aim 2: To examine the stability of the Time 1 model at Time 2 by testing measurement invariance.

Comparing models. To address Aim 2 (to examine the stability of the cognitive model of FCR), we tested the models from Time 1 and Time 2 simultaneously using the SEM analyses, described above. This procedure is testing measurement invariance, which involves a sequence of tests. The first step involves establishing configural invariance, which demonstrates that the same factor structure at Time 1 is also present at Time 2 (i.e., the same number of factors and the same indicators load on those same factors). The next involves testing metric invariance, and it builds upon configural invariance by requiring that in addition to the constructs being measured by the same items, the factor loadings of those loadings must be equivalent across time. Attaining invariance of factor loadings suggest that the construct has the same meaning to participants across administrations. To assess metric invariance, the factor loadings were constrained to be equal across the two time points. This constrained model represents a nested model within the

original model tested and thus allows for a chi square difference test to determine whether adding the equality constraints across loadings significantly worsens the model fit.

Aim 3: To test the predictive validity of the model. To address Aim 3, SEM was used to examine whether the components of FCR at baseline (Time 1) predicted consequences (behavioural responses) at Time 2. Specifically, the model included internal cues and the components of FCR at Time 1 and behavioural consequences at Time 2, while controlling for behavioural consequences at Time 1.

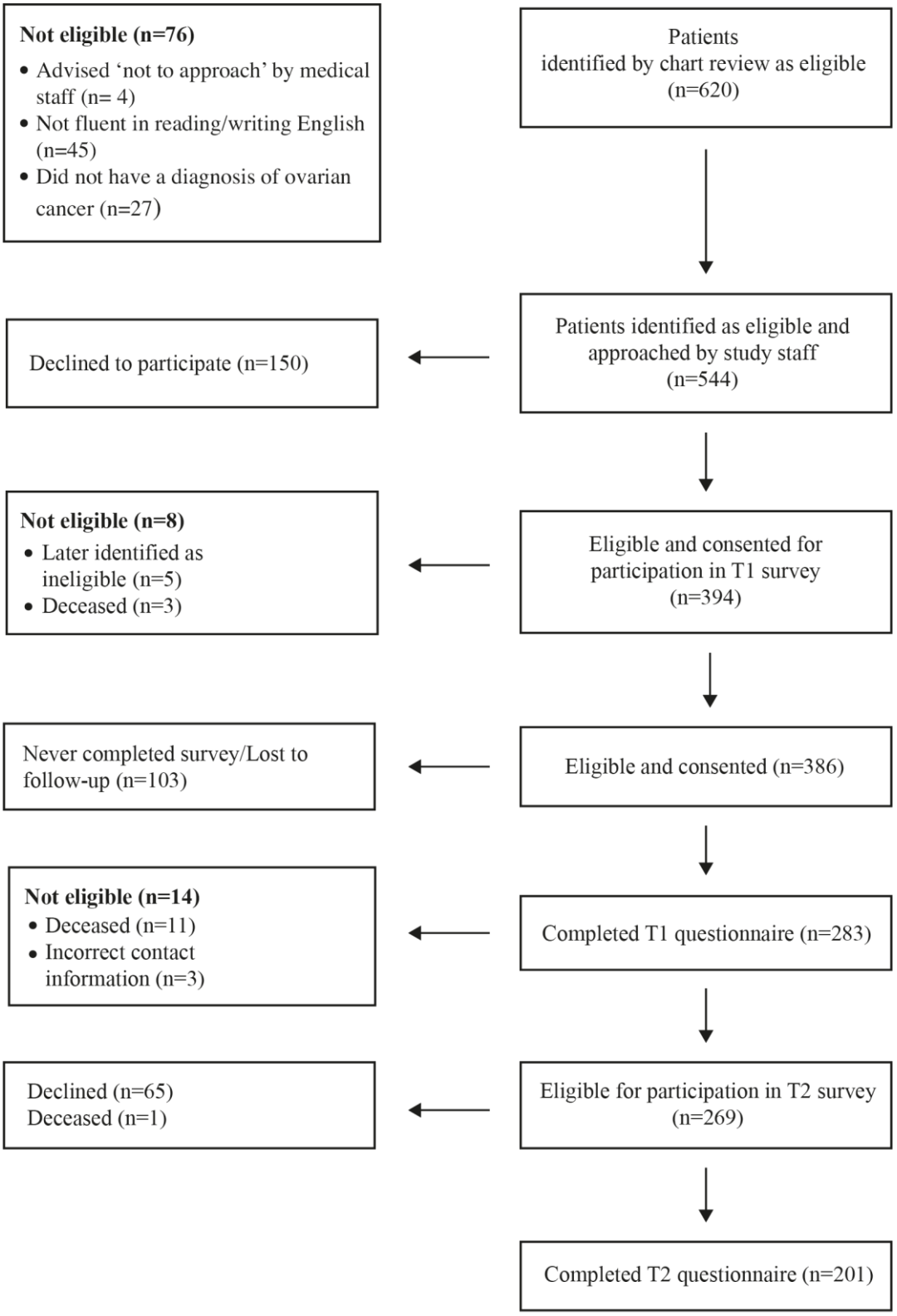

Figure 4. Flowchart of survey processes and responses among participants.

Results

Recruitment

Participants were recruited from the Gynecology Oncology Clinic at Princess Margaret Hospital (refer to Figure 4 for an overview of the study recruitment flow). A total of 620 patients were identified by chart review as eligible. Twenty-seven patients were classified as ineligible because they were diagnosed with a borderline or non-invasive tumour, 45 were unable to speak or read English, a member of the healthcare team recommended against approaching 4 patients. As a result, study staff approached a total of 544 patients, 150 of which declined to participate. Of those eligible (n = 336), 283 completed the Time 1 questionnaires while 150 declined and 103 never completed the survey or were lost to follow-up, resulting in a response rate of 52.8%. Of those eligible for participation in the Time 2 survey, 201 completed the Time 2 questionnaire, resulting in a response rate of 38.6% (201/521).

Descriptive Statistics

Two hundred and eighty three participants completed the Time 1 questionnaire *(*N = 283) and of those participants, 201 also completed the Time 2 package (N = 201). Table 1 displays the demographics of the full sample (N = 283). The average age for the sample was 57.95 years. The majority of the sample was Caucasian (75.6%) and highly educated, with 60.3% of patients reporting a college or university degree or higher education levels. In terms of employment, 38.5% of patients were working full- or part-time, 33.8% were retired, and 20.3% were on disability. Almost half of the sample (43.8%) reported an average income of between 0 to 40,000 dollars, whereas 28.3% of patients reported their average annual income to be greater than 75,000 dollars.

Table 1

Demographic Characteristics

Variable	N	%	M (SD)
Age (years)			57.95 (11.23)
Education			
High school	42	15.1	
Some post-secondary	69	24.7	
Post-secondary degree	114	40.9	
Graduate degree	54	19.4	
Employment			
Full-time	78	27.8	
Part-time	30	10.7	
Retired	95	33.8	
Disability	57	20.3	
Not employed	21	7.5	
Ethnicity			
Caucasian	214	75.6	
Black	12	4.2	
Asian	35	12.4	
Hispanic	5	1.8	
Other	12	4.2	
Income			
0 – 40,000	116	43.8	
40,000 – 75,000	74	27.9	
75,000+	75	28.3	

Note. *M* =Mean; *SD* = Standard Deviation

Medical characteristics of the patients are displayed in Table 2. The majority of patients were diagnosed with late-stage illness—69.4% of the sample was diagnosed with Stage 3 or 4 ovarian cancer. It had been an average of approximately three and a half years since diagnosis. Of the 54% of patients who were currently receiving treatment, 14.5% were undergoing primary treatment and 39.4% were undergoing treatment for recurrence. Almost 36% of patients were post primary treatment; of these, 91.1% patients were considered disease-free and 0.9% still had evidence of disease and were on active surveillance. Six percent of patients had experienced a recurrence in the past but were currently disease free, and 4.3% had experienced a recurrence and still had evidence of disease, but were not currently receiving treatment. Of the patients receiving treatment, all were receiving chemotherapy. Of these, approximately 23% were undergoing chemotherapy only, almost 18% were undergoing both surgery and chemotherapy, and approximately 3% were undergoing a combination of surgery, chemotherapy and radiation.

Additionally, 20.8% of the sample who completed the Time 2 survey reported experiencing a recurrence since completing their baseline (Time 1) measures (i.e., within the last 3 months). Independent samples t-tests revealed that those who experienced a recurrence differed significantly from those who did not on age, as well as several key study variables at Time 2.

Table 2

Medical Characteristics of the Sample

Variables	***N***	**%**
Stage of cancer		
Stage 1	63	22.4
Stage 2	23	8.2
Stage 3	162	57.7
Stage 4	33	11.7
Stage of Treatment		
Post primary treatment, disease free	92	32.6
Post primary treatment, disease present	9	3.2
Undergoing primary treatment	41	14.5
Past recurrence, now disease free	17	6.0
Recurrence, disease present, no treatment	12	4.3
Recurrence, on treatment	111	39.4
Current treatment		
Surgery only	17	6.2
Chemotherapy only	62	22.7
Surgery and chemotherapy	48	17.6
Surgery, radiation, and chemotherapy	8	2.9
Not currently receiving treatment	138	50.5

	N	***M (SD)***	***Range***
Time since diagnosis, in years	282	3.57 (3.51)	0-19.68

Note. M = Mean, *SD* = Standard Deviation

Those who experienced a recurrence were significantly younger (M = 52.05, SD = 13.18) than those who did not (M = 58.52, SD = 10.34), $t(185) = -3.27$, $p < .001$. Women who experienced a recurrence since completing baseline measures also endorsed more somatic stimuli at Time 2 (M = 20.80, SD = 2.86) than those who did not (M = 22.12, SD = 3.05), $t(163) = -2.29$, $p = .02$, and more physical symptoms (M = 18.53, SD = 7.02) than women without a recurrence (M = 22.13, SD = 5.11), $t(186) = -3.62$, $p < .001$. The two groups differed in their beliefs about the eradication of cancer $t(177) = -3.12$, $p = .002$, revealing that women who experienced a recurrence (M = .61, SD = 1.18) believed their cancer was cured significantly less than those who did not experience a recurrence (M = 1.40, SD = 1.39). Those who had a recurrence endorsed higher levels of perceived risk (M = 3.35, SD = 1.09) than those without a recurrence (M = 2.48, SD = 1.19), $t(181) = 4.06$, $p < .001$, seeking more advice (M = 3.58, SD = 1.98; M = 2.38, SD = 1.78, respectively), $t(171) = 3.40$, $p < .001$, having a higher increase in somatic anxiety (M = 40.67, SD = 15.87; M = 35.33, SD = 12.14, respectively), $t(186) = 2.30$, $p = .02$, and more panic attacks (M = 2.39, SD = 3.87; M = 1.15, SD = 2.39, respectively), $t(176) = 2.43$, $p = .02$.

Descriptive information for key study variables for the entire sample at Time 1 and Time 2 is displayed in Table 3, using the data from all the participants who completed Time 1 (n = 283) and all of those who completed Time 2 (n = 269). Findings are organized below according to the latent variables specified by the conceptual model, their indicators, and the specific scales used to measure them. When comparing differences between Time 1 and Time 2, only data from participants who completed both time points were used.

Table 3

Descriptive Statistics of Key Study Variables for the Entire Sample

Variables	**Mean (*SD*)**		
	Time 1 (N = 283)	**Time 2 (N = 201)**	**Possible Range**
Somatic stimuli	21.29 (3.22)	21.79 (3.12)*	14-28
Interpretation of symptoms	5.94 (3.09)	4.69 (3.41)*	0-13
Physical symptoms	21.14 (5.96)	21.51 (5.47)	0-28
Exposure to Cancer Cues	12.79 (5.53)	11.85 (5.63)	0-24
Family contact	28.95 (5.60)	24.32 (4.04)*	9-36
Predisposition	16.19 (5.34)	16.23 (5.48)	0-40
Past Coping Style	5.38 (1.91)	5.14 (4.01)	0-8
Cancer Experience	1.72 (1.10)	1.79 (.41)	0-5
Knowledge base	7.83 (2.44)	7.85 (2.39)	4-17
Beliefs eradication of cancer	1.24 (1.42)	1.27 (1.40)	0-4
Perceived risk	2.69 (1.22)	2.67 (1.21)	0-4
Worry about cancer recurrence	7.62 (4.68)	6.94 (4.63)	0-12
Anxiety about cancer	25.28 (8.03)	25.10 (7.84)	5-25
Treatment Decision Regret	24.35 (24.89)	19.74 (21.77)	0-100
Body checking	1.36 (1.32)	1.26 (1.17)	0-4
Seeking advice	2.83 (1.93)	2.61 (1.90)*	2-8
Limited planning for the future	6.24 (1.53)	6.38 (1.47)	0-8
Misinterpretation of symptoms	2.51 (1.81)	2.25 (1.29)*	0-8
Increased somatic anxiety	37.71 (13.46)	36.93 (13.40)	20-80
Panic attacks	2.08 (3.81)	1.50 (2.86)	0-28

Note. SD = Standard Deviation; * significant difference between Time 1 and Time 2, $p < .001$

Internal Cues

Somatic Stimuli. Cronbach's alpha for this scale was .79 at Time 1 and .76 at Time 2. As a higher score indicates less somatic stimuli, patients endorsed relatively little somatic stimuli at both time points. For those who completed both time points (n = 155), the mean at Time 1 was 21.12 (SD = 3.20) and for Time 2 it was 21.99 (SD = 3.07). A paired samples t-test revealed significant differences between Somatic Stimuli measured at Time 1 and Time 2, $t(154) = -2.54$, $p = .02$, demonstrating that on average, patients reported experiencing less somatic stimuli at Time 1 than at Time 2. However, the effect size was small, Cohen's d = .3.

Interpretation of Symptoms. Cronbach's alpha for the full subscale was .49. As the majority of the sample did not endorse experiencing the symptom "dizziness," removing this item improved reliability at Time 1 (α = .80) and Time 2 (α = .84). As a lower score reflects more attribution of physical symptoms as related to one's illness, our participants believed that their somatic symptoms were related to their illness. The format of the questionnaire first asks patients to indicate whether or not they experienced a certain symptom, and if they did to indicate whether or not they attribute that symptom to their illness. Many patients failed to complete the second part of the question (interpretation) and therefore the number of patients who completed this measure is lower than for the above scale. On average, patients (n = 92) endorsed experiencing more symptoms that were related to their illness at Time 1 (M = 6.20, SD = 3.11) than at Time 2 (M = 4.49, SD = 3.48), $t(91) = 3.48$, $p < .001$, with a moderate effect size, Cohen's d = .52.

Physical Symptoms. This measure demonstrated good reliability at both Time 1 (α = .88) and Time 2 (α = .86). The mean for both time points were relatively high, suggesting that on average, patients reported that they were experiencing physical symptoms "very much" of the time. Of those who completed both time points (n = 172) there was no significant difference in

physical symptoms reported between Time 1 (M = 20.96, SD = 5.63) and Time 2 (M = 21.47, SD = 5.54), $t(182) = -.41$, $p = .68$.

External Cues

Exposure to Cancer Cues. The scale demonstrated good reliability at Time 1 (α = .88) and excellent reliability at Time 2 (α = .92). Results suggest that patients were exposed to a moderate amount of cancer of cues at both time points. On average, patients who completed both time points (n = 173) reported being exposed to significantly more cancer cues at Time 1 (M = 13.12, SD = 5.55) compared to Time 2 (M = 11.80, SD = 5.65), $t(172) = 2.10$, $p = .04$. However the effect size for this difference was small, Cohen's d = .23.

Family Contact. The Openness of Discussion in the Family questionnaire demonstrated adequate reliability at both Time 1 and Time 2, with Cronbach's alphas of .72 and .77 respectively. Overall, patients appear to be open to discussing their cancer within their family. When comparing time points, patients (n = 152) on average reported more openness to discuss cancer with their family members at Time 1 (M = 28.58, SD = 5.41) than at Time 2 (M = 24.35, SD = 4.11), $t(151) = 8.08$, $p < .001$. The effect size for this difference was large, Cohen's d = .87.

Predisposition. The scale demonstrated good reliability at both time points (Time 1, α = .82; Time 2, α = .84). Overall patients in the current sample were not very high in optimism. There was no significant differences between the time points (Time 1 M = 15.97, SD = 5.12, Time 2 M = 16.22, SD = 5.52), $t(185) = -.49$, $p = .63$

Past Coping. This scale demonstrated acceptable reliability at Time 1 (α = .70) and Time 2 (α = .77). Patients frequently engaged in positive coping strategies. For those who completed both time points, responses at Time 1 (M = 5.45, SD = 1.92) and Time 2 (M = 5.09, SD = 2.0) did not differ significantly, $t(193) = 1.80$, $p = .07$.

FCR Cognitions

Past Cancer Experience. Given that this was a single item measure, reliability was not calculated. On average, patients in this sample had experienced approximately two prior cancer diagnoses (Time 1 M = 1.72, SD = 1.10, Time 2 M = 1.79, SD = .41).

Knowledge Base. Reliability of the full scale was poor (α = .66). Since a significant number of patients in the study were not currently receiving treatment, removal of the item that assessed "perceived knowledge about current treatment" resulted in scale improvement (Time 1, α = .80; Time 2, α = .79). The means suggest that the women in this sample perceived themselves to be relatively knowledgeable about ovarian cancer and its treatment. Among those who completed both time points (n = 187), there was no significant difference in responses on this measure between Time 1 (M = 7.99, SD = 2.37) and Time 2 (M = 7.84, SD = 2.42), t(186) = .61, p = .54.

Beliefs About Eradication of Cancer. Given that this was a single item measure, reliability was not calculated. Overall, patients believed that their cancer was cured to a small degree. There was no significant difference between Time 1 (M = 1.29, SD = 1.46) and Time 2 (M = 1.29, SD = 1.41), for those who completed both time points (n = 173), t(172) = .00, p = 1.00.

Perceived Risk of Recurrence. Given that this was a single item measure, reliability was not calculated. Women in this sample perceived their risk of recurrence to be moderately high. There was no significant difference between Time 1 (M = 2.68, SD = 1.20) and Time 2 (M = 2.68, SD = 1.22) for those patients who completed both time points (n = 177), t(176) = .04, p = .97.

FCR Emotions

Worry About Cancer Recurrence. This scale demonstrated excellent reliability (Time 1, α = .91; Time 2, α = .94.). The means suggest that the patients in this sample experienced relatively high levels of worry about cancer recurrence. Despite women reporting more worry on average at

Time 1 (*M* = 7.91, *SD* = 4.78) than at Time 2 (*M* = 6.99, *SD* = 4.69), the difference among those completed both time points (*n* = 174) was not statistically significant, *t*(173) = 1.83, *p* = .07.

Anxiety about Cancer. The reliability at both time points was excellent (Time 1, α = .94; Time 2, α = .95). The means revealed a moderate amount of anxiety about cancer in general in this sample. The difference between time points (Time 1 *M* = 25.93, *SD* = 7.91, Time 2 *M* = 25.16, *SD* = 7.83), was not significant, *t*(196) = .97, *p* = .34 among those who completed both time points (*n* = 197).

Treatment Decision Regret. Treatment decision regret was assessed using the Decision Regret Scale, which demonstrated excellent reliability at Time 1 (α = .91) and Time 2 (α = .90). The means reflect a low amount of decision regret. There was no significant difference between Time 1 (*M* = 24.12, *SD* = 24.62) and Time 2 (*M* = 19.63, *SD* = 22.32), *t*(156) = 1.78, *p* = .08 for patients who completed both time points (*n* = 157).

Behavioural Responses

Body Checking. As body checking was assessed using a single item from the FCRI, reliability was not calculated. The means suggest that the patients in this sample engaged in a moderately low amount of body checking. Among those who completed both time points (*n* = 164), there was no significant difference between Time 1 *(M* = 1.32, *SD* = 1.31) and Time 2 (*M* = 1.23, *SD* = 1.19), *t*(163) = .72, *p* = .47.

Seeking Advice. Given that this scale only contained two items, the reliability was poor at both time points (Time 1, α = .41; Time 2, α = .43). This is not surprising given that recent research suggests that the conditions for Cronbach's alpha are unreasonable for a composite scale, causing the coefficient alpha to almost always underestimate true reliability, sometimes rather substantially (Bollen, 1989; Revelle & Zinbarg 2009, Sijtsma, 2009). As such, the

coefficient alpha has been argued to be inappropriate for two-item scales (Eisinga, te Grontenhuis, & Pelzer, 2012). In this situation, it has been suggested that a preferable alternative to Cronbach's alpha is to calculate the mean inter-item correlation for the items, with optimal mean inter-item correlation values range from .15 to .50 (Hulin & Cudeck, 2001; Clark & Watson, 1995). As such, the inter-item correlation for this measure was calculated and found to be within the acceptable range at .46 at Time 1 and .27 at Time 2, and therefore this measure was retained in the model. Patients in this sample reported engaging in a low to moderate amount of advice seeking. On average, patients reported that they sought significantly more advice at Time 1 (M = 2.83, SD = 1.93) than at Time 2 (M = 2.15, SD = 0.89), $t(159) = 2.34$, $p = .02$.

Limited Planning for the Future. The full scale demonstrated poor reliability (α = .28). Removing three items that were less explicitly related to planning for the future (e.g., "I live one day at a time") resulted in acceptable reliability at Time 1 (α = .78) and good reliability at Time 2 (α = .80). The items that remained were: "I like to make plans for the future" and "I find it helpful to set goals for the near future." The answer options ranged from 1 (*a lot*) to 4 (*not at all*), and were reverse coded. The means for those completed both time points (n = 187; Time 1 M = 6.29, SD = 1.57; Time 2 M = 6.39, SD = 1.47) suggest that the patients in this sample engaged in little planning for the future. $t(186) = -.59$, $p = .56$.

Psychological Effects

Misinterpreting Symptoms. Given that this scale only contained two items, the reliability was poor at both time points (Time 1, α = .63; Time 2, α = .57). As previously mentioned, given the limitations of the Cronbach's alpha for two-item scales, the inter-item correlation was calculated for this measure and found to be within the acceptable range at .46 at Time 1 and .42 at Time 2, and therefore this measure was retained in the model. On average, patients (n = 169)

reported a significantly higher tendency to misinterpret their symptoms at Time 1 (M = 2.61, SD = 1.96) compared to Time 2 (M = 2.25, SD = 1.31), $t(190) = 2.12$, $p < .05$.

Increase in Somatic Anxiety. This scale demonstrated excellent reliability at both time points (Time 1, α = .96; Time 2, α = .96). The means suggest that the patients in this sample had a moderate amount of somatic anxiety. There was no significant difference between time points (n = 189; Time 1 M = 38.32, SD = 13.60; Time 2 M = 36.94, SD = 13.47), $t(188) = .98$, $p = .33$.

Increased Propensity to Panic Attacks. This scale demonstrated excellent reliability at Time 1 (α = .92) and good reliability at Time 2 (α = .86). The means at both time points were very low, which reflects that very few women in the sample endorsed experiencing panic attacks. There was no significant difference between those who completed both time points (n = 164) at Time 1 (M = 2.04, SD = 3.63) and Time 2 (M = 1.50, SD = 2.73), $t(163) = 1.49$, $p = .14$.

Given the study's focus on FCR, the overall severity endorsed in our sample was examined using the FCRI severity subscale. Using the recommended cut-off of 13 (Simard & Savard, 2015), the current sample was well in the clinical range for FCR severity at both Time 1 (M = 21.51; SD = 7.59) and Time 2 (M = 20.26; SD = 7.76).

Preliminary Analyses

To assess the normality of the distributions, skewness and kurtosis of each of the key measures were assessed. Skewness and kurtosis were deemed to be minimal if the respective *z*-scores fell between ±2.58 ($p < .01$). Analyses revealed a non-normal distribution for the panic attacks measure at Time 1, (skew = .27, kurtosis= 5.14, *SE* =.16) and Time 2 (skew = 2.39, kurtosis = 5.81 *SE* = .18) as responders must have experienced a panic attack in the past 6 months in order to complete the measure. As less than 6% of the sample endorsed experiencing a panic attack in the past 6 months, the variable of panic attacks was dropped from the model. All other measures demonstrated normal distributions.

Multivariate skewness was observed, Mardia's skew = 29.78, $p < .001$, but multivariate kurtosis was not an issue ($Z = 1.02$, $p = .31$). In an attempt to correct for bias arising from multivariate skew, a Satorra-Bentler correction was used, which is a robust adjustment for non-normal data (Harlow, 2014). The use of this correction method did not result in any differences from the model that used maximum likelihood (ML) estimation with no adjustments. Given that ML estimation can handle slight to moderate departures from normality particularly for skewness (Joreskog & Sorbom, 1993), the non-corrected models were retained.

Given that recent recommendations indicate that model-specific power be calculated as opposed to using general rules of thumb (Wolf, Harrington, Clark & Miller, 2013), power was calculated using a program that generates R code that can compute statistical power for testing a covariance structure model (MacCallum et al., 1999). These calculations resulted in a power estimate of .95 for the baseline model and .83 for the model at Time 2, demonstrating adequate sample size.

Hypothesis Testing

Aim 1: To test the cognitive model of FCR (Lee-Jones et al., 1997) in an ovarian cancer sample. It was hypothesized that our data would support the model illustrated in Figure 2. We expected to see each component of the model supported by the latent variables (e.g., internal and external cues were expected to be associated with FCR cognitions and emotions as outlined by the model, which in turn were expected to be associated with the consequences of behavioural responses and psychological effects).

Step 1. **Examining the measurement model at both time points: Exploratory Factor Analysis.** Two separate EFAs were conducted on Time 1 and Time 2 using SPSS.24 (IBM Corp. Released 2016) to determine how the sub-components loaded onto the latent variables. Maximum likelihood estimation with promax rotation was used because despite some minor deviations from normality that were found, there were no significant deviations from multivariate normality. Moreover, it was anticipated that the latent variables were not independent or uncorrelated, so a varimax rotation would not have been appropriate. The EFA revealed five components at both time points, with eigenvalues over Kaiser's criteria of 1 and in combination explained 67.50% of the variance at Time 1 and 63.25% of the variance at Time 2; see Figure 5 for a graphical representation. Table 4 shows the factor loadings after rotation for Time 1 and Table 5 shows the factor loadings at Time 2. A factor loading for a variable is a measure of how much the variable contributes to the factor. Higher factor loadings indicate that a variable is closely associated with the factor, with scores greater that .40 to be considered statistically meaningful (Tabachnick & Fidell, 2007). Contrary to our hypothesis, the data did not support the model illustrated in Figure 2. Firstly, results suggested a five-factor model, as opposed to the six-factor model proposed by Lee-Jones et al. (1997). External cues and

psychological effects did not come out as their own factors. Consistent with the cognitive model, somatic stimuli, interpretation of symptoms, and physical symptoms clustered on the same component of internal cues. Consistent with our hypotheses, worry about cancer recurrence and anxiety about cancer, clustered on the same component of emotional experience, however counter to the model, other items also clustered onto this component. Specifically, chance exposure and predisposition, which were posited as external cues, and misinterpretation of symptoms and increased somatic anxiety, which were suggested as psychological effects according to Lee-Jones et al. also loaded onto emotional experience. These items that load onto the same component are all related to a more complex emotional experience than Lee-Jones et al.'s (1997) model posited. Indeed, these findings are in line with the conceptualization that an emotional experience includes physiological, cognitive, and behavioural components (Barlow, Allen, & Choate, 2004; Barlow et al., 2010; Boisseau, Farchione, Fairholme, Ellard, & Barlow, 2010; Wilamowska, Thompson-Hollands, Fairholme, Ellard, Farchione & Barlow, 2010). Additionally, treatment regret did not load onto any component in a meaningful way. Consistent with the model, belief in the eradication of cancer and perceived risk clustered together on appraisals of cancer diagnosis, however past cancer experience and knowledge base did not load onto any component. As such, these indicators more specifically reflect appraisals of cancer prognosis. As predicted, body checking and seeking advice clustered together to comprise behavioural responses. Limited planning for the future loaded onto its own factor unexpectedly, but it had no significant regression paths to other variables in the model, and was therefore not included in the analyses or in Figure 5, in which circles denote latent constructs and squares denote manifest indicator variables.

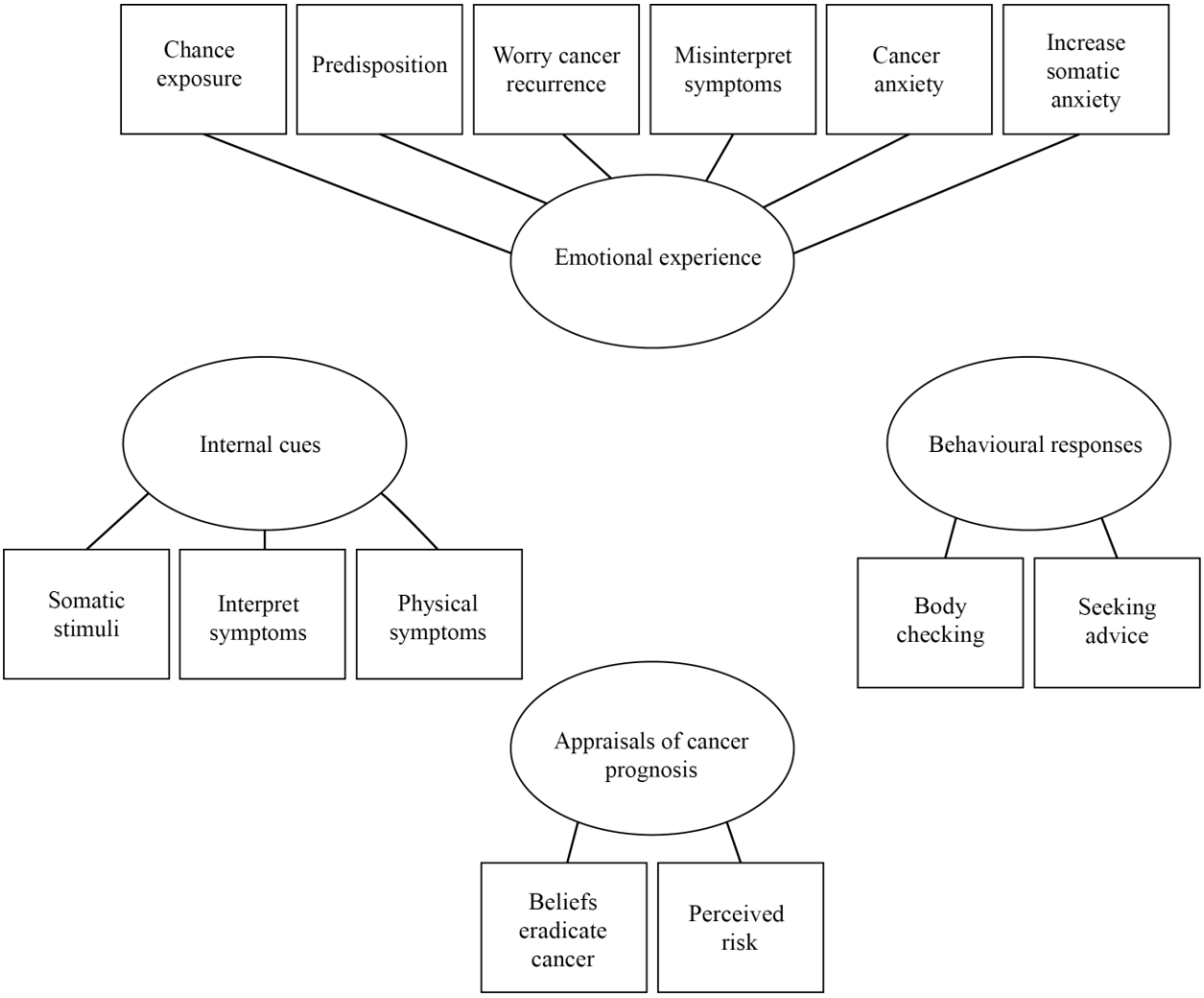

Figure 5. The model according to the EFA results.

Table 4

Table with Factor Loadings after Promax Rotation for Time 1

	Emotional Experience	**Internal Cues**	**Appraisals of Cancer Prognosis**	**Behavioural Responses**	**Limited Future Planning**
Somatic Stimuli	-.26	**-.90**	-.25	-.09	.23
Interpretation of Symptoms	.30	**.84**	.26	.15	-.02
Physical Symptoms	-.40	**-.54**	-.28	-.20	.30
Chance Exposure	**.72**	.24	.23	.32	-.21
Family Contact	-.11	-.07	.02	.01	.17
Predisposition	**-.46**	-.12	-.05	-.11	.36
Past Coping	-.10	.01	-.16	.20	.38
Belief Eradication of Cancer	-.16	-.22	**-.66**	.03	.23
Perceived Risk	.38	.33	**.98**	.16	-.16
Worry Cancer Recurrence	**.87**	.31	.30	.34	-.39
Anxiety about Cancer	**.84**	.29	.21	.28	-.36
Body Checking	.27	.07	-.02	**.67**	.05
Seeking Advice	.23	.11	.09	**.83**	.15
Misinterpretation of Symptoms	**.77**	.48	.31	.37	-.51
Increased Somatic Anxiety	**.75**	.33	.23	.31	-.55
Limited Future Planning	-.13	-.08	-.14	.11	**.52**

Note: Extraction Method: Maximum Likelihood; Rotation Method: Promax with Kaiser Normalization; Bolded numbers represent the highest factor loadings, indicating that the variable is closely associated with the factor.

Table 5

Table with Factor Loadings after Rotation for Time 2

	Emotional Experience	**Internal Cues**	**Appraisals of Cancer Prognosis**	**Behavioural Responses**	**Limited Future Planning**
Somatic Stimuli	-.19	**-.84**	-.24	-.13	.24
Interpretation of Symptoms	.27	**.96**	.32	.09	.08
Physical Symptoms	-.36	**-.67**	-.26	-.23	.14
Chance Exposure	**.67**	.23	.26	.25	-.01
Family Contact	-.31	-.19	-.17	.09	.41
Predisposition	**-.48**	-.03	-.05	-.14	.36
Past Coping	-.10	.01	-.24	.13	.25
Belief Eradication of Cancer	-.17	-.16	**-.66**	.07	.16
Perceived Risk	.31	.38	**.94**	-.02	-.12
Worry Cancer Recurrence	**.86**	.24	.30	.15	-.25
Anxiety about Cancer	**.88**	.19	.18	.15	-.16
Body Checking	.23	.09	-.09	**.99**	.02
Seeking Advice	.15	.20	.03	**.53**	.01
Misinterpretation of Symptoms	**.51**	.25	.22	.23	-.01
Increased Somatic Anxiety	**.74**	.37	.21	.16	-.32
Limited Future Planning	-.09	-.08	-.13	.05	**.67**

Note: Extraction Method: Maximum Likelihood; Rotation Method: Promax with Kaiser Normalization; Bolded numbers represent the highest factor loadings, indicating that the variable is closely associated with the factor.

Step 2. Specifying the structural model: Structural equation modeling. Using the results of the EFA, structural equation modeling (SEM) was used to analyze the model shown in Figure 6. Because appraisals of cancer prognosis and behavioural responses only had two measured variables, one of the factor loadings was constrained to 1 in order to identify the latent variables (Kline, 2015). The initial model demonstrated adequate model fit χ^2 (62, N=283) = 162.29, p < .001, χ^2/df = 2.63, CFI = 0.93, RMSEA = .08, SRMR = .06. The model was therefore revised according to theoretically meaningful modification indices, which suggest changes to the model that improve fit. The largest sensible modifications were implemented first, which included adding an error covariance to the indicators chance exposure and increase in somatic anxiety, as well as to increase in somatic anxiety and physical symptoms. This error covariance suggests that there is a meaningful relationship between these indicators above what is being captured by their relationship to the latent variables. These modifications were theoretically meaningful and will be discussed further in the Discussion section.

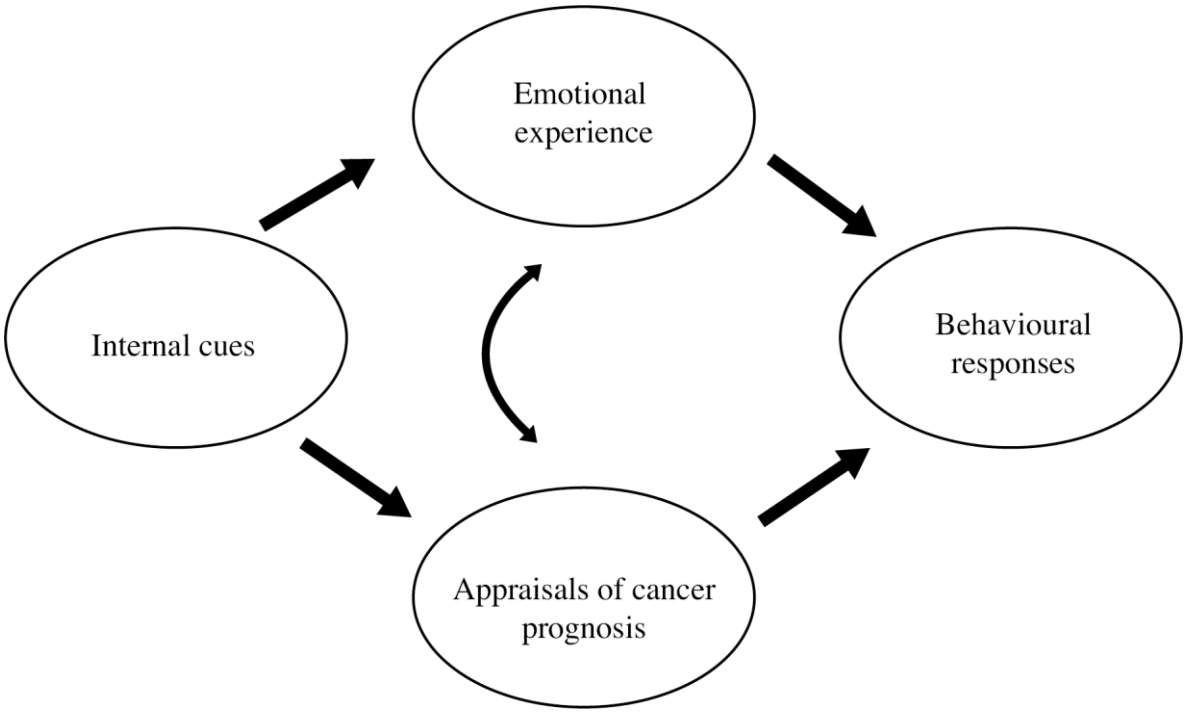

Figure 6. The structural model according the EFA results.

Results of the revised model revealed excellent model fit at Time 1, χ^2 (60, N = 283) = 130.48, $p < .001$, $\chi^2/df = 1.84$, CFI = 0.95, RMSEA = .06, SRMR = .06. It is important to note when evaluating the regression paths that given the reverse scoring of the indicators, which comprise internal cues (aforementioned in the methods section), a lower score on internal cues means higher levels of the indicators. As predicted, these results reveal that internal cues were significantly associated with the emotional experience of FCR and appraisals of cancer prognosis. This relationship was stronger for appraisals of cancer prognosis than the emotional experience, with results reflecting a large and moderate strength relationship, respectively. In turn, the emotional experience was moderately but significantly related to behavioural responses, such that the stronger the emotional experience, the more one engages in behaviours (i.e., body checking and seeking advice) as a response. In contrast and contrary to our hypothesis, appraisals of cancer prognosis were not significantly related to behavioural responses. A path diagram is shown in Figure 7, and parameter estimates are displayed in Table 6. In terms of internal cues, interpretation of symptoms accounted for the most variance of this latent variable, followed by somatic stimuli, then physical symptoms. Perceived risk accounted for more variance in appraisal of prognosis relative to beliefs about the eradication of cancer. In terms of the emotional experience, worry about cancer recurrence was the indicator with the relatively largest contribution to this factor, followed by anxiety about cancer and misinterpretation of symptoms. Increase in somatic anxiety and chance exposure accounted for slightly less variance, and predisposition accounted for the least variance in the emotional experience. Lastly, body checking contributed more significantly to behavioural responses than seeking advice.

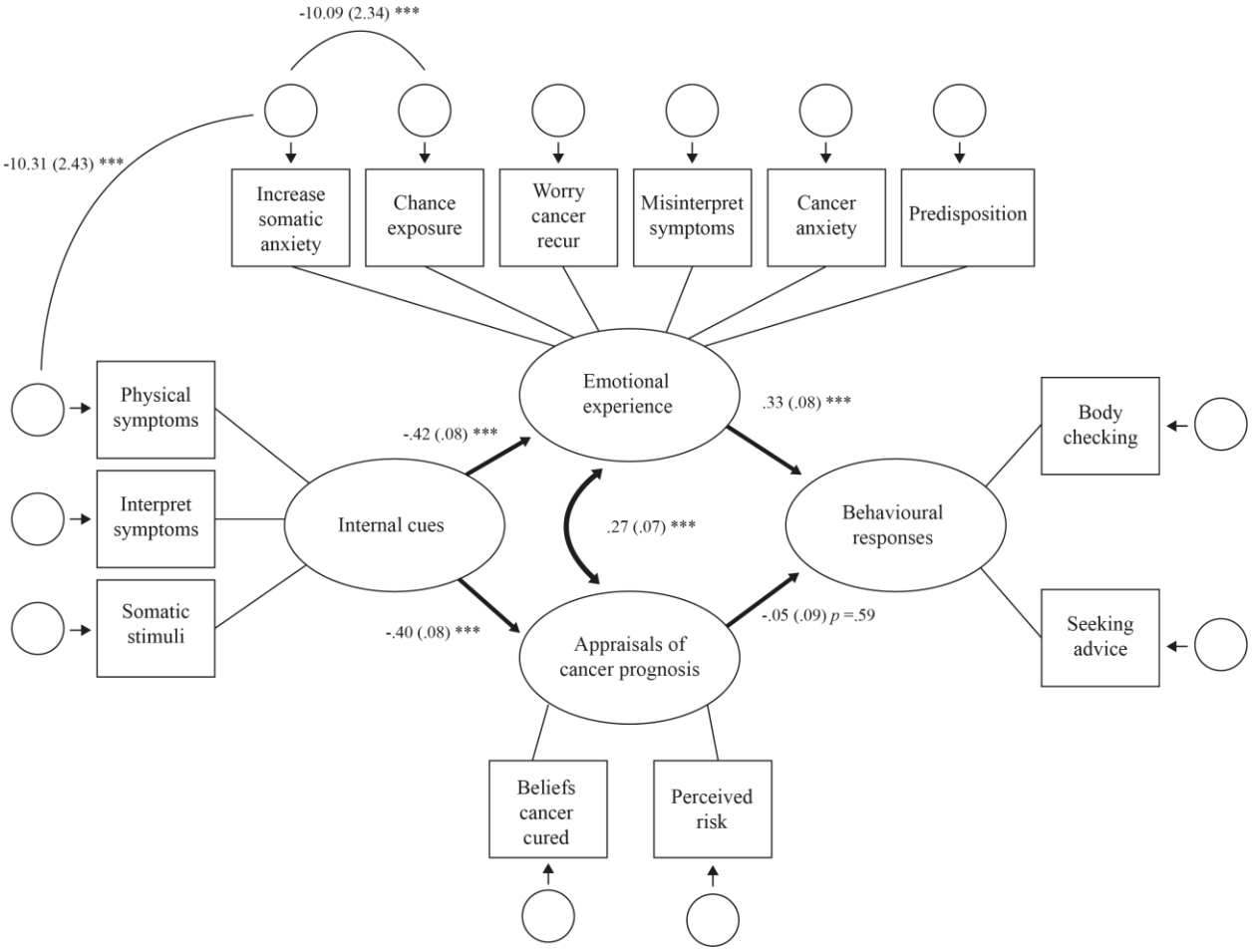

Figure 7. Aim 1. The revised model at Time 1 (with error covariance), χ^2 (60, N = 283) = 130.48, $p < .001$, CFI = 0.95, RMSEA = .06, SRMR = .06, $\chi^2/df = 1.84$.

*$p < .05$. ** $p < .01$. *** $p < .001$. Circles denote latent constructs, squares denote manifest indicator variables, and straight bolded lines with arrows represent structural paths. Curved bolded lines represent covariance, and curved unbolded lines represent error covariance.

Table 6

Aim 1. Standardized and Unstandardized Parameter Estimates for the Revised Model at Time 1

Variable	**β**	**B**	***SE***	***Z***	***p***
Internal Cues					
Somatic Stimuli	0.86	2.76	0.19	14.56	.001
Interpretation of Symptoms	-0.89	-2.84	0.21	-13.58	.001
Physical Symptoms	0.55	3.29	0.37	8.99	.001
Appraisals of Cancer Prognosis					
Beliefs about Eradication of Cancer	-0.65	-0.86	0.09	-10.15	.001
Perceived Risk	0.96	1.00*	-	-	.001
Emotional Experience					
Chance Exposure	0.74	3.74	0.28	13.21	.001
Predisposition/Optimism	-0.46	-2.27	0.29	-7.72	.001
Worry Cancer Recurrence	0.86	3.66	0.22	16.38	.001
Anxiety about Cancer	0.82	6.03	0.39	15.59	.001
Misinterpretation of Symptoms	0.79	6.20	0.44	14.20	.001
Increase in Somatic Anxiety	0.76	9.17	0.65	14.02	.001
Behavioural Responses					
Body Checking	0.98	1.00*	-	-	.001
Seeking Advice	0.70	1.27	0.15	8.30	.001

Note. These parameters were constrained to 1 to identify the latent variable. β represents standardized estimates; B represents unstandardized estimates; SE denotes standardized error.

Aim 2: To examine the stability of the Time 1 model at Time 2 by testing measurement invariance. It was hypothesized that the components of the model described in the previous section would be equivalent at Time 2 (three months post-baseline). As such, the same model from Figure 7 was tested at Time 2. Results suggested that the model fit was acceptable; χ^2 (60, N = 201) = 121.15, $p < .001$, χ^2/df = 2.02, CFI = 0.93, RMSEA = .07, SRMR = .07, thus confirming that configural invariance was met. Results supported the hypothesis that the factorial structure is equal across time, and the same indicators measure the same underlying constructs at Time 1 and at Time 2. For a graphic representation of the Time 2 model with latent variable regression coefficients, refer to Figure 8, for individual parameter estimates see Table 7. Metric invariance was then tested by constraining the factor loadings at Time 1 and Time 2 to be equal. The model at the configural stage was compared to the metric model using a chi square difference test. The chi square difference test was statistically significant, $\chi^2(11)$ =165.75, $p <$ .001 and there was a large change in model fit, ΔCFI = -.067, ΔRMSEA =.028, ΔSRMR = .053. Because the difference in model fit significantly worsened, this suggests that factor loadings are not invariant across time, meaning the constructs have different meaning or significance to patients at Time 1 compared to Time 2. Misinterpretation of symptoms had the most substantial change in factor loadings across time points, making a larger contribution to the emotional experience at Time 2 (standardized coefficient = .79) compared to Time 1 (standardized coefficient = .54). The indicators for behavioural responses also demonstrated relatively large changes in loadings from Time 1 to Time 2, demonstrating that body checking was relatively more important at Time 1 (standardized coefficient = .98) relative to Time 2 (standardized coefficient = .89), as was seeking advice (Time 1 standardized coefficient = .55; Time 2 standardized coefficient = .46). Further tests of invariance (e.g., equality of means or error variances) are inappropriate if previous

stages of invariance are not met. Therefore, subsequent stages of invariance were not tested for, and while the model structure is stable over time, there are differences in the model parameters (e.g., loadings). For ease of comparison between the two time points and for descriptive purposes, Table 8 shows the standardized coefficients from Time 1 and Time 2.

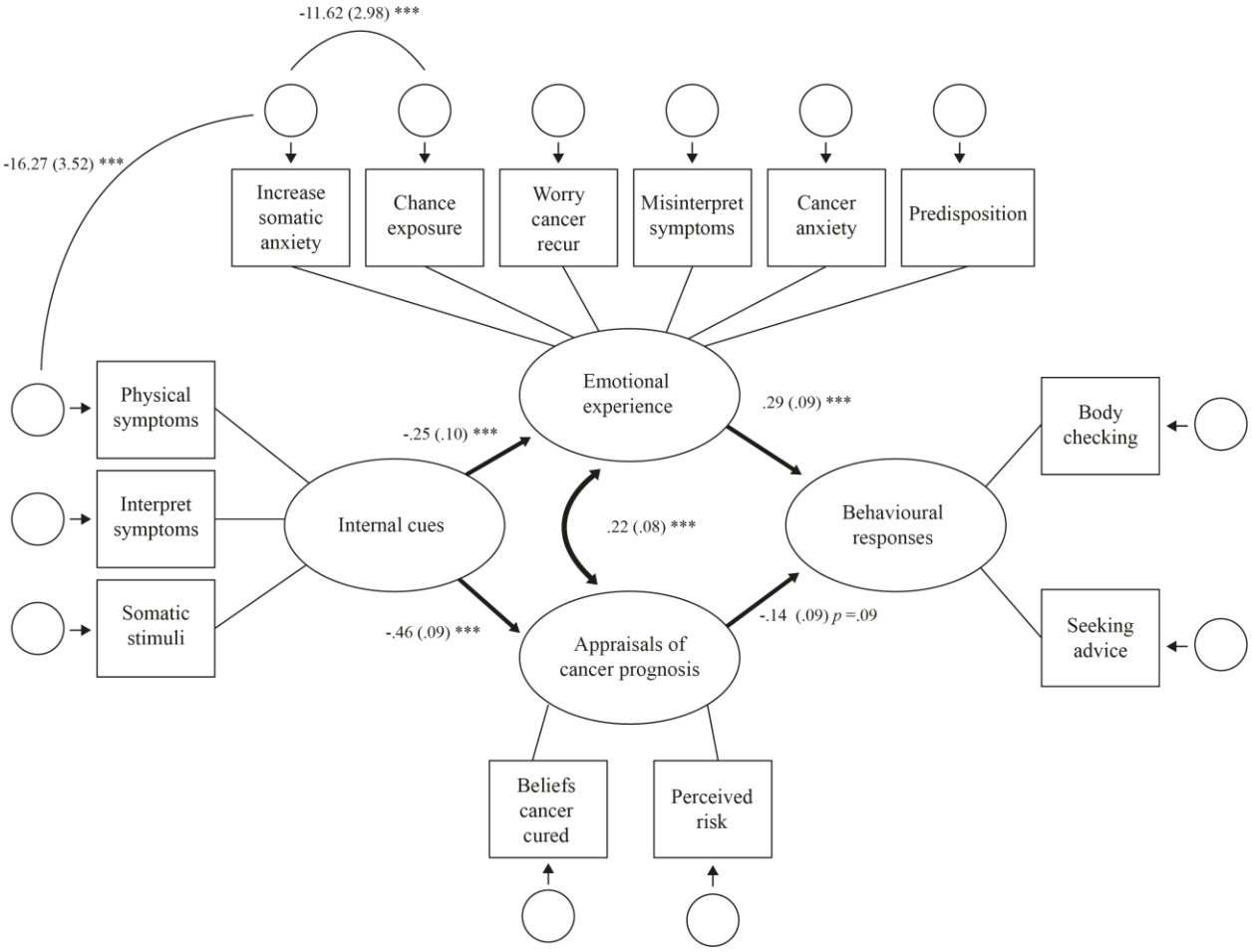

Figure 8. Aim 2. Testing the stability of the model at Time 2 (with error covariances), χ^2 (60, N = 201) = 121.15, $p < .001$, CFI = 0.93, RMSEA = .07, SRMR = .07, $\chi^2/df = 2.02$.

*$p < .05$. ** $p < .01$. *** $p < .001$. Circles denote latent constructs, squares denote manifest indicator variables, and straight bolded lines with arrows represent structural paths. Curved bolded lines represent covariance, and curved unbolded lines represent error covariance.

Table 7

Aim 2. Standardized and Unstandardized Parameter Estimates for the Stability of the Revised Model at Time 2.

Variable	β	B	*SE*	*Z*	*p*
Internal Cues					
Somatic Stimuli	0.82	2.56	0.21	12.09	.001
Interpretation of Symptoms	-0.92	-3.05	0.23	-13.48	.001
Physical Symptoms	0.62	3.33	0.38	8.67	.001
Appraisals of Cancer Prognosis					
Beliefs about Eradication of Cancer	-0.64	-0.79	0.10	-8.32	.001
Perceived Risk	0.95	1.00*	-	-	.001
Emotional Experience					
Chance Exposure	0.70	3.75	0.36	10.30	.001
Predisposition	-0.47	-2.44	0.37	-6.55	.001
Worry Cancer Recurrence	0.86	3.77	0.27	13.79	.001
Anxiety about Cancer	0.85	6.30	0.44	13.95	.001
Misinterpretation of Symptoms	0.54	0.66	0.08	7.77	.001
Increase in Somatic Anxiety	0.72	8.72	0.75	11.48	.001
Behavioural Responses					
Body Checking	0.89	1.00*	-	-	.001
Seeking Advice	0.46	0.84	0.16	5.26	.001

Note. These parameters were constrained to 1 to identify the latent variable. β represents standardized estimates; B represents unstandardized estimates; *SE* denotes standardized error

Aim 3: To test the predictive validity of the model. In order to test the predictive validity of the emotional experience and appraisals of cancer prognosis, a revised SEM model was estimated whereby internal cues, the emotional experience and appraisals of cancer prognosis at Time 1 predicted behavioural consequences at Time 2, while controlling for behavioural consequences at Time 1. Results indicated that using the components of FCR at Time 1 to predict consequences at Time 2 resulted in adequate model fit, χ^2 (84, N = 283) = 167.17, p < .001, CFI = 0.94, RMSEA = .06, SRMR = .07, χ^2/df = 1.99; however, the regression paths from the emotional experience and appraisals of cancer prognosis were not significant predictors of behavioural responses at Time 2 (refer to Figure 9).

Table 8

Descriptive Table for Comparison of Parameter Estimates at Time 1 Relative to Time 2 in the Evaluation of Metric Invariance.

Variable	Time 1 β	Time 2 β
Internal Cues		
Somatic Stimuli	0.86	0.82
Interpretation of Symptoms	-0.89	-0.92
Physical Symptoms	0.55	0.62
Appraisals of Cancer Prognosis		
Beliefs about Eradication of Cancer	-0.65	-0.65
Perceived Risk	0.96	0.96
Emotional Experience		
Chance Exposure	0.74	0.70
Predisposition/Optimism	-0.46	-0.47
Worry Cancer Recurrence	0.86	0.86
Anxiety about Cancer	0.82	0.85
Misinterpretation of Symptoms	0.79	0.54
Increase in Somatic Anxiety	0.76	0.72
Behavioural Responses		
Body Checking	0.98	0.89
Seeking Advice	0.70	0.46

Note. β represents standardized estimates; B represents unstandardized estimates

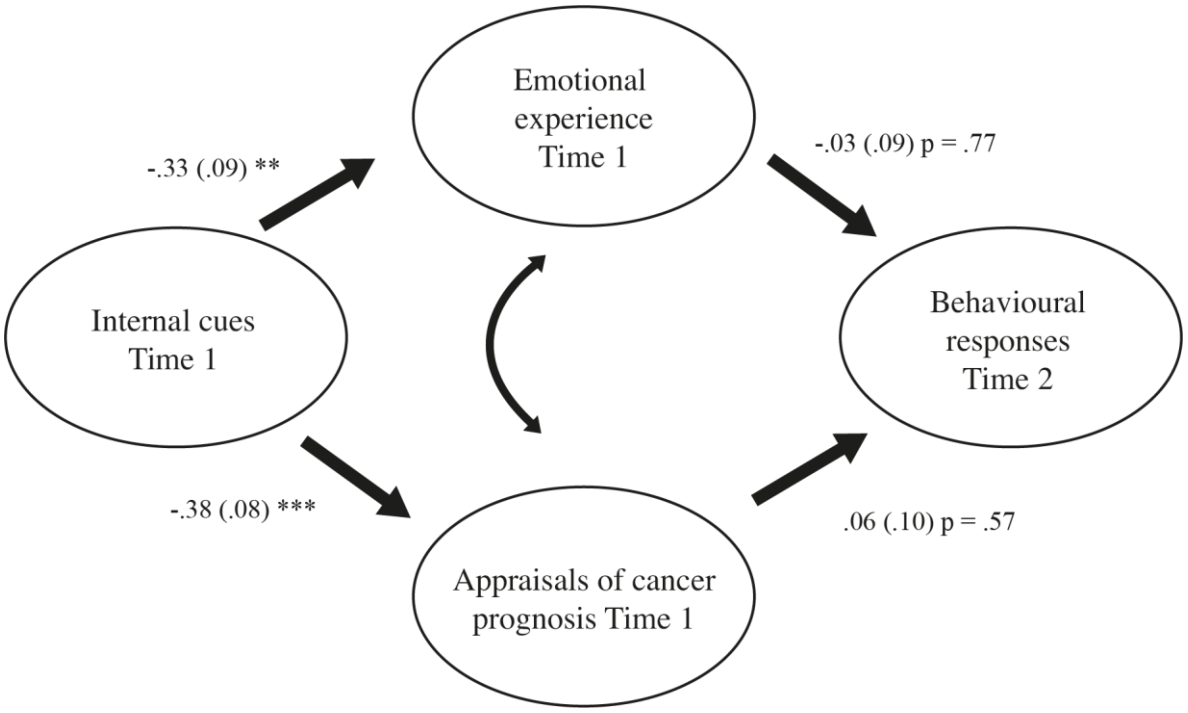

Figure 9. Aim 3. Using the components of FCR at Time 1 to predict consequences at Time 2 resulted in adequate model fit, $\chi 2$ (84, N = 283) = 167.17, $p < .001$, CFI = 0.94, RMSEA = .06, SRMR = .07, $\chi 2/df = 1.99$.

Discussion

Overview of the Results

The present study tested the cognitive model of FCR proposed by Lee-Jones and colleagues (1997). This was the first known study to: (1) empirically test the full cognitive model of FCR using structural equation modeling; (2) examine the stability of the model over two time points; and (3) test the predictive validity of the model.

The results of the exploratory factor analysis suggested a more parsimonious five-factor model, as opposed to the six-factor model proposed by Lee-Jones et al. (1997). Structural equation modeling (SEM) was then used to analyze the model as outlined by the EFA results. Results revealed that the more internal cues endorsed by patients, the stronger the emotional experience and the more negative the appraisal of their prognosis. In turn, the stronger the emotional experience, the more one engaged in behaviours (i.e., body checking and seeking advice) as a response. In contrast, appraisals of cancer prognosis were not significantly related to behavioural responses. In order to test the temporal stability of the model, a metric invariance test was conducted to examine the stability of the model across the two time points. The results revealed that the factorial structure was equal across time, and the same indicators measured the same underlying constructs at Time 1 and at Time 2. However, the factor loadings were not invariant across time, meaning the constructs have different meaning or significance to patients at Time 1 compared to Time 2. To evaluate the predictive validity of the model, SEM was used to test whether the model at Time 1 (i.e., internal cues, emotional experience, and appraisals of cancer prognosis) predicted behavioural consequences at Time 2, and results indicated that the model at Time 1 was not a significant predictor of behavioural responses at Time 2.

Understanding the Sample

Medical characteristics. Within the present sample, 70% of patients were diagnosed with late-stage cancer, which is comparable to prior research suggesting that approximately 75% of women with ovarian cancer present with stage III or IV disease (Davey, 2007). This has important implications for prognosis, as survival is inversely related to disease stage; patients with stage I, II, III, and IV ovarian cancer have median 5-year survival rates of approximately 93%, 70%, 37%, and 25%, respectively (Armstrong, 2002). Importantly, the 1-year recurrence rate for stage III-IV patients is 30.3%, which is significantly higher than stage I-II patients, whose rate is 2.7% (Zhang, Li, & Chen, 2003). Additionally, after an initial recurrence, generally 70% of advanced stage ovarian cancers relapse again, compared to a relapse rate of 20%-25% in patients with stage I or II cancer (Ushijim, 2010). The majority of women in the present study were not coping with an initial cancer diagnosis, given that patients in this sample reported an average of two prior cancer diagnoses prior to Time 1. Research has demonstrated that patients experience the initial cancer diagnosis differently than a recurrence. For example, in a recent review of breast cancer survivorship, Conley and colleagues (2016) asserted that initial diagnosis focuses the patient on mobilizing resources in the short term, as well as seeking and gaining knowledge about the disease and treatment options. In contrast, recurrence requires coping in the long term, which may include ongoing monitoring and regular surveillance, additional treatment for recurrence or secondary cancer, and continued care and support (Conley, 2016; Stein, Syrjala, & Andrykowski, 2007). As such, the women in this study may have already shifted their perception to view their cancer as a chronic condition, rather than an acute one, which may have important implications for their emotional experience, which is discussed in depth under Aim 1. It is noteworthy that fear of progression and FCR are terms used interchangeably in the literature,

and are not treated as distinct conceptualizations. Indeed, the recent agreement about the definition of FCR as being "fear, worry, or concern about cancer returning or progressing in the same place or another part of the body" was partially motivated to clarify confusion regarding whether these differing terminologies represented distinct underlying constructs. Furthermore, many of the fear of progression and FCR measures have significant overlap.

The goal of treatment for recurrent ovarian cancer is controlling the disease and disease-related symptoms, limiting treatment-related toxicity, and maintaining or improving quality of life (Jemal et al., 2004). Nevertheless, the time length to first relapse varies widely, from a few months to more than five years (Herzog, 2004). In the current sample, 20.8% of patients experienced a recurrence in the 3-month interval between the two time points assessed. Further investigation of this subset revealed that those who had a recurrence between Time 1 and Time 2 were younger, reported more physical symptoms and somatic stimuli, less strongly believed that their cancer was cured, endorsed higher perceived risk of cancer, sought more advice, reported higher somatic anxiety, and reported more panic attacks. These differences are not surprising but are important to highlight in the description of our sample. The fact that they are younger suggests they might be earlier on in their cancer journey and experiencing their first, prognostically "expected" recurrence. Being less confident that their cancer is cured and having higher perceived risk is likely an accurate appraisal and they would have likely sought more advice due to the increased symptoms that may have been indicative of recurrence. The more physical symptoms, somatic symptoms, and somatic anxiety may likely be attributed to those associated with recurrence or side effects of a new treatment regimen. However, it is also possible that it may also reflect a decreased tolerance for physical symptoms. A recent study by Frey and colleagues (2017) demonstrated that women with ovarian cancer are willing to accept

many treatment side effects when the goal of treatment is curative, but this acceptance wanes in the face of recurrence, once the goal shifts from being cured to attaining remission and maintaining stable disease. Indeed, research has demonstrated that the general trend is one whereby patients desire cure at the time of diagnosis, but then their goal shifts to maintaining quality of life later on in the disease course, particularly following a recurrence (Erwin, 2010; Frey et al., 2014; Fried, Bradley, Towle, & Allore, 2002; Fried, Van Ness, Byers, O'Leary, & Dubin, 2007). As such, this shift may underlie heightened attention to and subsequently more reporting of physical symptoms.

Demographic characteristics. The average age of participants was approximately 58 years old, similar to other studies of ovarian cancer patients recruited from tertiary hospital settings (e.g., Bodurka-Bevers et al., 2000; Carmack-Taylor et al., 2004; Danhauer et al., 2008). Additionally, our sample was predominantly Caucasian, well-educated, affluent, and largely employed, with 38.5% still working full or part-time. These demographics are consonant with the majority of studies in the literature on ovarian cancer (see Ozga et al., 2015 for a review). While the similarity in demographics across studies potentially limits our ability to generalize our findings to more diverse samples, it does facilitate comparisons to prior research.

Fear of cancer recurrence. The overall severity of FCR endorsed in our sample was examined, and results demonstrated that participants' scores were well in the clinical range for FCR severity at both Time 1 and Time 2. Given the disease course, prognosis, and recurrence rates associated with ovarian cancer (National Cancer Society, 2014), FCR has recently been identified as ovarian cancer-specific symptom that is prevalent and severe (Ozga et al., 2015). However, despite this increasing awareness, our understanding of FCR among ovarian cancer

patient remains limited due to the lack of studies examining the clinical severity of FCR in an ovarian cancer population using the FCRI.

Aim 1: Testing the FCR Model

The components of the model. The results of this study are partially consistent with Lee- Jones et al.'s cognitive model of FCR (1997). Lee-Jones and colleagues suggested a six-factor model that included internal cues, external cues, FCR emotions, FCR cognitions, behavioural responses and psychological effects. Our results suggested a more parsimonious four-factor model that included internal cues, the emotional experience, appraisals of cancer prognosis, and behavioural responses. Importantly, most indicators of external cues and psychological effects posited by Lee-Jones et al. were also maintained in the model, only subsumed under different factors.

Internal cues. Analogous to Lee-Jones et al.'s cognitive model, somatic stimuli, interpretation of symptoms, and physical symptoms clustered on the same component of internal cues. The current sample of women reported a great deal of physical symptoms and interpreted these as related to their illness. This is an expected finding given that treatment typically involves debulking surgery, followed by multiple rounds of chemotherapies, along with unpleasant side-effects, including hair loss, pain, intestinal blockages, neuropathy, and cognitive decline (Ushijima, 2010). Indeed, prior data show many women interpret their physical symptoms to be an indicator that their cancer has progress or returned (Ferrell et al., 2003; Shinn et al., 2009).

Emotional experience. In line with Lee-Jones et al., our data suggest worry about cancer recurrence and anxiety about cancer in general cluster together on the same component. However, our results also suggest that chance exposure (e.g., medical appointments and examinations, conversations about cancer), misinterpretation of symptoms, increase in somatic

anxiety, and predisposition (i.e., low optimism) were part of this same factor. As such, our data show that medical appointments and pessimism do not "trigger" FCR as originally proposed by Lee-Jones et al., but are an integral part of the emotional experience itself, along with the worry about recurrence and anxiety about cancer. Similarly, misinterpreting symptoms and increase in somatic anxiety were not found to be psychological consequences of FCR, but part of the emotional experience as well. These associations are consistent with the premise that an emotional experience contains physiological, cognitive and behavioural components (Barlow et al., 2005; Wilamowska et al., 2010). Indeed, Barlow and colleagues (2004) posit that an emotional experience includes antecedents (triggers) as well as cognitive, behavioural, and physiological responses (Wilamowska et al., 2010). This line of research draws on affective neuroscience and emotion and learning theories, which outline that during emotional experiences, the brain is using prior experience to dynamically interpret ongoing neural activity, which guides an individual's responding in the situation. This process often occurs without awareness, as it is a fundamental process for making sense of one's relation to the world at any given moment, and is referred to as situated conceptualization (Barrett, Mesquita, Ochsner, & Gross, 2007; Wilson-Mendenhall, Barrett, Simmons, & Baralou, 2011). According to this approach, conceptualizing a situation in a particular way causes it to be experienced as an emotion. In this process, the term 'situated' refers to the broad and distributed neural activity across the modal systems of the brain involved in constructing situations, not just to perception of the external environment. More specifically, situated neural activity that comprises emotional experiences reflects the dynamic actions that individuals engage in, and the events, internal bodily sensations, and mentalizing that they experience, as well as the perceptions of the external environmental setting (Wilson-Mendenhall et al., 2011).

Furthermore, the association between these constructs that make up the emotional experience in this study are consistent with the premise of emotional conditioning, wherein the pairing of the conditioned stimulus (CS; e.g., chance exposure such as medical appointments) and unconditioned stimulus (US; e.g., fear and anxiety) leads to the expectation that the CS will be followed by the US (i.e., expectancy-based learning), causing autonomic responses (e.g., somatic symptoms; Hamm & Vaitl, 1996; LeDoux, 1995, Ohman et al., 1998). In the context of ovarian cancer, the high frequency of medical appointments and physical symptoms may be so frequently paired with fear and anxiety in time that they become a conditioned stimulus, and occur in tandem with worry and anxiety, becoming inextricable. Indeed, the link between follow-up appointments and heightened anxiety and worry about recurrence has been documented in a significant amount of research among ovarian cancer populations (Cesario et al., 2010; Ferrell et al., 2003; Mirabea-Beale, 2009; Reb, 2007; Stewart et al., 2001). This is particularly relevant for the current sample, given that most patients had an average of two prior cancer diagnoses prior to entering the study, and after an initial recurrence, generally 70% of advanced stage ovarian cancers relapse again (Ushijim, 2010). Consequently, these women have had many occurrences where the anxiety and fear associated with the medical appointments and examinations, along with the physical symptoms they experienced, was reinforced with devastating results, strengthening the relationship between these constructs. Overall, the findings from this study depict a more comprehensive emotional experience as a component of FCR that includes elements that are in line with current conceptualizations of the main components of an emotional experience.

Appraisals of cancer prognosis. In line with Lee-Jones et al.'s (1997) formulation, perceived risk of a recurrence and beliefs about the eradication of initial cancer were components of the same factor. However, Lee- Jones and colleagues posited that past experiences with cancer

and knowledge base would also comprise this component, and these indicators were not retained in the current data-based model. This may be due to the lack of variability in these measures in our participants. For example, a large majority of the sample had already received at least one prior cancer diagnosis, creating a relatively homogenous sample in this regard. Relatedly, most patients in the sample reported perceiving themselves to be reasonably knowledgeable about ovarian cancer and the course of the disease. Given that the knowledge base question was created for this study and consisted of a single-item measure, it is also possible that it did not accurately capture this construct. However, given the homogeneity of the sample (late stage ovarian cancer), it is also possible that there is less variability in the course of their cancer and therefore less nuanced information provided, leading many to feel they have a good understanding of what to expect. Overall, the results from study reflect a factor that contains cognitive processes more specifically related to the appraisal of their cancer prognosis compared to the model posited by Lee-Jones et al. (1997).

Behavioural responses. Lastly, the behavioural responses component of the model was highly consistent with Lee-Jones et al.'s formulation; indicators that loaded onto this component were body checking and seeking advice. Treatment decision regret did not load onto any factors in the EFA in a meaningful way, and analyses demonstrated that there was low decision regret in the current sample. One possible explanation for this finding is that it reflects another important distinction in the experience of early relative to advanced stage cancer. For example, the concept of treatment decision regret may be more relevant in the treatment of early-stage breast cancer where there are options for more or less conservative procedures (e.g., lumpectomy or mastectomy) or a more prophylactic approach (e.g., double mastectomy). Conversely, while ovarian cancer patients have choices for treatment, such as the option of surgery and different

chemotherapies, there is a complex algorithm of treatment choices that oncologists use to advise treatment. Most patients with advanced stage ovarian cancer will eventually fail primary chemotherapy, and second line therapy may be considered (du Bois, 2001). Disease that relapses after initial chemotherapy often responds poorly to conventional chemotherapy. Many of these patients are thus eligible for clinical trials of new medications. A response to chemotherapy may result in relief of symptoms and an improvement in quality of life and may be worthwhile even when associated with significant side-effects. However, it is likely that only a small minority of patients would achieve such a response with new phase II drugs and it is difficult to predict in advance who these patients will be (Poole, de Takats, & Earl, 1994). In this context, decision making on the part of the patient may involve deciding between opting for a potentially toxic treatment, which may have a negative impact on quality of life with a small chance of remission versus no further active treatment other than that aimed at symptom relief.

However, the low level of treatment decision regret endorsed by the current sample is consistent with research showing many patients are willing to undergo intensive treatment even in the knowledge that a favourable outcome is unlikely. For example, in a study asking patients who were about to receive chemotherapy the percentage of benefit that would make intensive chemotherapy worthwhile, 53% of 106 patients were willing to have intensive treatment for a 1% chance of cure and 42% would accept the same treatment for only a three month prolongation of life. There was no significant change in participants' responses three months after reciept of chemotherapy (Slevin et al., 1988). As such, treatment regret may be an important factor that differs between early and late-stage cancers, or at least early stage breast cancer and advanced ovarian cancer.

Lee-Jones et al. had also posited that limited planning for the future would also be part of behavioural responses; interestingly, it came out as its own factor in the EFA and was not significantly related to any other component in the model. Further examination of the data revealed that the women in this sample were engaging in very little, if any, planning for the future. This may indicate awareness and acceptance of poor prognosis, given the stage of cancer, number of recurrences already experienced, and the significant proportion of women who experienced a recurrence while participating in this study. Because there is no cure for recurrence, treatment eventually becomes ineffective, and/or patients decide they no longer want to endure the effects of treatment and choose to stop chemotherapy (Zabora et al., 2001). On average, women survive 12 to 18 months following a recurrence, with fewer than one in ten surviving more than five years (Tummala & McGuire, 2005). Indeed, a qualitative study of women diagnosed with ovarian cancer found that women described recurrence as being a denial of a future and a death sentence (Cesario et al., 2010).

Interestingly, in their recent examination of the Lee- Jones et al. model, Custers and colleagues demonstrated that the models with limited planning for the future as a behavioural consequence showed the largest effects (Custers et al., 2017). However, this study examined the relationships in the model separately using 12 regression analyses. Specifically, 12 conceptual models tested the associations between four types of cues (internal, e.g., “feeling sick” and bodily sensations) and external (“media and social context” and contact with health professionals) and three types of behavioural responses (limited planning for the future, seeking professional advice, and body checking), with FCR as the mediator variable. It is difficult to compare the results of Custers et al.’s study to the current study, given the significant differences in design and statistical approach, however it suggests that further examination of limited

planning for the future is warranted. Additionally, it is important to note that the eligible population in Custers et al.'s (2017) study was a sample of breast cancer survivors who were disease free and treated with curative intent. Therefore, the samples differed significantly in important disease-related characteristics. Qualitative analysis may be an appropriate method for future research, which may provide a richer understanding for women with ovarian cancer.

Error covariances. Error covariances are included in a structural equation model when indicators are shown to share a theoretically meaningful commonality above and beyond the factor they load onto. In the current model, an error covariance was added to the indicators chance exposure and increase in somatic anxiety. A large area of literature that supports chance exposure (i.e., external cues) as triggers of FCR is the research on post-traumatic stress disorder and the cancer experience. This research has demonstrated that physical and psychological responses to continual and necessary cancer surveillance can cause hyperarousal states related to external cues, causing the patient to re-experience the emotional distress and physical pain that may have occurred during diagnosis and treatments (Custers et al., 2016). A second error covariance was added to physical symptoms and increase in somatic anxiety. The relationship between these two constructs is well established in the anxiety literature, particularly in the context of interoceptive conditioning, wherein physical symptoms that occur with an increase in anxiety or panic become associated together, leading the occurrence of one to elicit the onset of the other (Ohman et al., 1998).
Our data provide important empirical validity to the components of the model as outlined by Lee-Jones et al. (1997). Despite minor differences in indicators of the components, most constructs stipulated by Lee-Jones and colleagues were retained in the model. Those components that were not retained in the model may reflect sample characteristics or measurement considerations as mentioned above. The largest observed discrepancy from Lee-

Jones et al.'s (1997) proposed model was with regards to the indicators that comprised the FCR emotional experience, suggesting that this component of FCR may be far more complex and multidimensional for women with ovarian cancer.

The Relationship Between Components of the Model

Internal cues and FCR. The results of the current study demonstrated that internal cues (i.e., physical symptoms, somatic stimuli, interpretation of symptoms) were significantly associated with both the emotional experience and appraisals of cancer prognosis, as theorized by Lee-Jones et al. (1997). This study adds to the strong evidence for the relationship between the presence or severity of physical symptoms and FCR (Deimling et al., 2006; Liu et al. 2011; Mast, 1998; Matulonis et al., 2008; Mehnert et al., 2004; Mellon et al., 2007; Mellon & Northouse, 2001; Schlairet, 2011). These findings have also been found in relation to treatment-related side effects, including fatigue, pain, sleep difficulties and abdominal pain, and greater FCR (Matulonis et al., 2008), which is highly relevant for the current sample, as 43.9% of the sample was undergoing primary treatment or on treatment for recurrence.

The components of FCR. Given the lack of a theorized direction for the relationship between the components of FCR outlined by the cognitive model, the emotional experience and the appraisals of cancer prognosis were included as covariances in the model. As expected, these components significantly covaried.

FCR and behavioural responses. Only the emotional experience was significantly associated with behavioural responses (e.g., body checking, seeking advice). Indeed, one of the most basic and important functions of emotion is to direct people toward a specific set of behaviour that would be adaptive to the situation at hand; these behaviours generally serve an adaptive function, allowing us to respond quickly to our environment to increase our likelihood

of survival (Barlow et al., 2010). Indeed, even though Barlow and colleagues suggest that behaviours are a component of the emotional experience, they also outline that intense emotional experiences lead to motivated behavioural responses, which they refer to as emotion-driven behaviours (Barlow et al., 200; Barlow et al., 2010; Boisseau et al., 2010; Wilamowska et al., 2010). Women with ovarian cancer have described experiencing the diagnosis as a death sentence, given the high rate of recurrence and low survival rate (Reb, 2007). Consequently, the direct threat to survival may cue emotion-driven behaviours with less cognitive mediation compared to patients with a cancer diagnosis that has more variability in course and survival, such as early-stage breast cancer. The findings of the current study may suggest that there are different processes that drive behavioural responses in late-stage or more aggressive cancers that more directly threaten one's survival.

Theoretical Implications

The current findings suggest that Lee-Jones et al.'s formulation of FCR provides a good basis to describe the experience of women with late stage ovarian cancer. The most commonly utilized theoretical framework for the recent interventions to treat FCR is Leventhal's CSM, likely because Lee-Jones et al.'s full conceptual model has not been comprehensively evaluated prior to this study. The central tenet of Leventhal's model (1980) is that individuals hold distinct and idiosyncratic beliefs, or representations, of their illnesses that influence coping responses, and, in turn, influence emotional or behavioural outcomes. Specifically, in the application of the CSM to FCR, it has been suggested that *perceived risk* serves as the link between internal and external cues and FCR. Additionally, according to the CSM, it is the perception of risk that leads to maladaptive coping behaviours, including anxious preoccupation, excessive body checking,

and reassurance seeking. However our results do not support this link, and suggest that the driving force behind these behaviours is the emotional experience.

While a significant amount of research has used the CSM to guide examination of the coping behaviours used in a diverse range of chronic diseases, including chronic fatigue syndrome (Moss-Morris, Petrie, & Weinman, 1996), psoriasis (Fortune, Richards, Main, & Griffiths, 2000), multiple sclerosis (Vaughan, Morrison, & Miller, 2003) and rheumatoid arthritis (Scharloo, Kaptein, Weinman, Hazes, Breedveld, & Rooijmans; Treharne, Lyons, Booth & Kitah, 2005), these illnesses are not directly life threatening. Although the CSM has been applied to FCR in breast cancer patients, it has predominantly been examined in early-stage diagnosis. This population also has a very different course and prognosis, often with several possible trajectories of disease. Therefore, the emphasis on illness representations and cognitive appraisals may allow for important clarification of misinformed perception of risk and improve maladaptive coping responses. Indeed, the applicability of the CSM is often used to highlight the high level of distress experienced by women who believe that their breast cancer is a chronic, uncontrollable disease with devastating social consequences, even after being told that they are in remission and have a favourable prognosis (Rabin et al., 2004). In such cases, the illness representation is inaccurate and adjustments to these cognitive appraisals could result in reduced distress and maladaptive behaviours. However, there is only one trajectory for late stage ovarian cancer, and the experience of recurrence serves to add a time limit to this trajectory. Importantly, ovarian cancer survivors have reported viewing a recurrence as an indication that their disease was incurable and considered it to be “the beginning of the end” (Ferrell at al., 2003). In this population, worry about recurrence, pessimism, anxiety about cancer and interpretation of physical symptoms may be accurate, and their medical follow-ups may provide more definitive

answers about their prognosis. As a result, these constructs cluster together, and serve to drive their behavioural responses. The results of this study suggest that a more parsimonious version of the Lee-Jones et al. model captures the FCR emotional experience in women with late stage ovarian cancer well, and given the key differences with the CSM, suggest that this model may be a more appropriate model for this population. Future research would benefit from replication of this study and the continued empirical evaluation of Lee-Jones et al.'s model in different cancer populations, particularly advanced cancers with less favourable prognoses, as this may have important treatment implications, which will be discussed in the clinical implications section.

Additionally, future research may benefit from incorporating components that have been proposed to be relevant FCR since the formulation of the cognitive model. For example, the cognitive processing model of FCR (Fardell et al., 2016) posits that positive or negative metacognitions (beliefs about worry) are likely to play a significant role in FCR (Fardell et al., 2016; Smith et al., 2018). Additionally, recent research has identified existential issues, specifically death anxiety, as being an overlooked construct that is likely associated with FCR, and may be particularly relevant for advanced cancers (Sharpe, Curran, Butow, & Thewes, 2018). As such, metacognitions and death anxiety may be important components to include in the cognitive model going forward.

Aim 2: Examining the Stability of the Model

The results of this study demonstrated that the model of FCR was highly stable across the two time points, and make an important contribution to the dearth of longitudinal studies of FCR. Prior research has examined the course of FCR in cancer survivors by using different methodologies (Ames et al., 2009; Burstein, Gelber, Guadagnoli, & Weeks, 1999; Costanzo et al., 2007; Deimling, Bowman, Sterns, Wagner, & Kahana, 2006; Kornblith et al., 2007; Sarkar et

al., 2014; Savard & Ivers, 2013; Stanton, Danoff-Burg, & Huggins, 2002; van den Beuken-van Everdingen, Peters, de Rijke, Schouten, van Kleef & Patijn, 2008; Vickberg, 2003). Cross-sectional studies examining FCR as a function of time since diagnosis in long-term cancer survivors suggest stable levels of fear over time (Deimling, Bowman, Sterns, Wagner, & Kahana, 2006, Koch et al., 2014; Kornblith et al., 2007; van den Beuken-van Everdingen et al., 2008; Vickberg, 2003). For example, Koch and colleagues (2014) examined FCR in long-term breast cancer survivors who were on average eight years post diagnosis, and concluded that even years after diagnosis and completion of routine follow-up care has ended, FCR is a clinically relevant issue for these women (Koch et al., 2014).

Longitudinal studies, on the other hand, mostly suggest that the highest levels of FCR are reported immediately after diagnosis and during treatment, which is followed by a decrease after treatment and stability after a few months in breast cancer survivors (Bloom, Stewart, Chang, & Banks, 2004; Lebel, Rosberger, Edgar, & Devins, 2007; Lebel, Rosberger, Edgar, & Devins, 2009; Wade, Nehmy, & Koczwara, 2005), and other types of cancer survivors (Ames et al., 2009; Sarkar et al., 2014; Savard & Ivers, 2013). For example, a recent large-scale longitudinal study by Savard and Ivers (2013) examined the evolution of FCR during the cancer care trajectory across several cancer sites, including breast, prostate, gynaecological, head and neck, and urinary gastro-intestinal (Savard & Ivers, 2013). Participants completed assessments at six time points: baseline (T1), two (T2), six (T3) 10 (T4), 14 (T5), and 18 months (T6). Although patients were recruited before surgery, 81.2% of them completed baseline measures after (20 days after on average). The findings revealed that FCR levels were highest at baseline, then significantly decreased at T2 and stabilized thereafter. Reasons for the high level of FCR at the time of diagnosis remain to be understood, however it has been speculated that it is related to the heightened psychological distress that occurs

at the time of diagnosis, which is usually correlated with FCR (Crist & Grunfeld, 2012). It has also been suggested that this finding reflects a regression to the mean, where more extreme scores tend to be followed by values closer to the mean. This hypothesis appears especially plausible in relation to Savard and Ivers' (2013) finding that patients with clinical FCR at baseline had a much greater reduction from T1 to T2 when compared with non-clinical levels.

However, some studies report stable levels throughout the entire follow-up period in breast cancer survivors (Burstein, Gelber, Guadagnoli, & Weeks, 1999; Costanzo et al., 2007; Stanton, Danoff-Burg, & Huggins, 2002). In a study of head and neck cancer patients, patient-reported FCR data was captured prospectively post-treatment over a period of 29 months, with results demonstrating that FCR was stable over this time period (Ghazali et al., 2013). These findings are also consistent with Savard and Ivers' (2013) finding that despite decreasing from T1 to T2, the scores of the patients remained above the clinical threshold at all subsequent time points in the study, which emphasizes the persistence of FCR when it reaches a certain severity level. Severity may explain some of the inconsistent findings over time, in that once FCR reaches a certain threshold, it remains stable throughout the follow-up. Our knowledge of the trajectory of FCR is increasing as research continues to develop and expand in this area, however, additional longitudinal studies are warranted in order to continue to refine our understanding.

Findings from our study also highlight the stability of FCR across time at many different stages of treatment, following and during a recurrence. In addition to demonstrating that overall levels of FCR are stable across a 3-month interval in patients with ovarian cancer, the current study is the first to our knowledge to evaluate the relative stability of the components of a data-driven model of FCR based on Lee-Jones et al.s' cognitive model (1997). Results suggest that there was a relatively strong stability in the components, with only two indicators demonstrating

a relative shift in importance between the two time points; misinterpretation of symptoms had a larger contribution to FCR emotions at Time 1 relative to Time 2, and body checking was a larger contributor to behavioural responses at Time 1 relative to Time 2. Likely, because patients reported that they misinterpreted their symptoms more at Time 1 than at Time 2, the indicator misinterpretation of symptoms accounted for more variance in the factor FCR emotions at Time 1 relative to Time 2 as well.

One variable found to influence perception and interpretation of symptoms is the length of time since being diagnosed (Kornblith et al., 2010). Further examination of this link in the current study revealed that time since diagnosis was only significantly related to misinterpreting symptoms at Time 2, such that the longer time since one was diagnosed the less one endorsed misinterpreting symptoms. Therefore, the longer patients have to adapt to their disease, the less they may misinterpret bodily sensations or changes. Indeed, research examining adjustment to illness trajectories has demonstrated significant reductions in anxiety related to physical symptoms as patients become familiar with treatment side effects (Ganz et al., 2002, Helgeson & Tomich, 2008). It has been demonstrated that long-term breast cancer survivors have been found to have increased physical impairment and symptoms, yet they do not report poorer quality of life or psychosocial function compared to age-matched controls (Ganz et al., 1998).

Another explanation for the drop in misinterpretation of symptoms may be methodological. Our measure for misinterpreting bodily sensations asks patients to reflect on their experience in the previous six months; these symptoms may have subsequently been examined at a follow-up appointment that occurred in between the study assessments. If patients received an explanation for these symptoms from their physicians, this may have resulted in

lower scores on this measure at Time 2 and led to less relative importance of the indicator misinterpreting bodily sensations to FCR emotions.

The amount of body checking endorsed also decreased from Time 1 to Time 2. Further examination of this relationship revealed that misinterpretation of symptoms was significantly associated with body checking at Time 1, suggesting that the more patients were misinterpreting their symptoms the more they engaged in body checking. However, these variables were not significantly related at Time 2. It is important to note that symptoms of ovarian cancer recurrence are non-specific and very difficult to distinguish from benign bodily sensations or changes. These symptoms include persistent abdominal bloating or indigestion, changes in appetite (typically a loss of appetite or feeling full sooner), pressure in the lower pelvis or back, and increased abdominal girth (Goff et al., 2006). As body checking played a less important role in behavioural responses relative to seeking advice at Time 2, this may support the hypothesis that patients could have had their symptoms evaluated at a medical appointment, leading to less self-checking and possibly more follow-up appointments being scheduled, as evidenced by seeking advice contributing more to behavioural responses at Time 2. Although our data cannot confirm this idea, this would be useful to examine in future research.

This is the first study to our knowledge to evaluate body checking across time, and only two studies to date have assessed body-checking behaviour in the context of FCR. In a cross-sectional study, Thewes and colleagues (2012) found that for breast cancer patients who recently finished treatment, greater FCR was associated with more frequent self-reported use of breast self-examination. In another cross-sectional study, breast cancer survivors who had more severe FCR reported more frequent use of checking as a strategy to cope with FCR (Custers et al., 2016). Although not directly examined in the current study, our data may support this link.

Indeed, FCR scores decreased from Time 1 (*M* = 21.51; *SD* = 7.59) to Time 2 (*M* = 20.26; *SD* = 7.76), and body checking decreased as well. Although body checking has been theorized as a consequence of FCR that provides short-term distress reduction but ultimately maintains FCR and reinforces checking behaviour (e.g., Fardell et al., 2016; Ghazali et al., 2012; Lasry & Margolese, 1992; Lee-Jones et al., 1997; Stark & House, 2000; Ziner et al., 2012), limited research has directly examined the construct in the context of FCR. The findings from the current study make a significant contribution to the literature by suggesting that body checking may be closely related to misinterpreting symptoms, which suggests a potential avenue for intervention.

To summarize, findings from Aim 2 suggest that the components of the FCR model as are largely stable across a three-month time period in women with ovarian cancer. This is the first study to our knowledge to examine components of FCR prospectively across time, and as such replication and extension studies are warranted. Examining the stability across longer time points and other cancer populations are important next steps for future research.

Aim 3: Evaluating the Predictive Validity of the Model

Unexpectedly**,** the results of the current study failed to support the predictive validity of the model, as specific components of the model (i.e., internal cues, the emotional experience, and appraisals of cancer prognosis) at Time 1 were not found to predict behavioural responses at Time 2. One possible explanation is that this is a methodological shortcoming, reflecting that the time between the assessments was too long to capture the impact on behaviour. For example, given the high level of physical symptoms and anxiety endorsed by the sample, it is conceivable that participants would seek advice sooner than 3 months, resulting in this consequence not being captured by the model at Time 2. An alternative approach to examining predictive validity of FCR is ecological momentary assessment (EMA), such as a daily diary. These measures are

typically completed in the evening and ask individuals to look back on the events of the day, which increases the likelihood of capturing relevant behaviours and reduces reliance on memory (Moskowitz & Young, 2006). An EMA approach has been successfully utilized in research with cancer populations, including using daily diaries to examine the diurnal pattern of off-treatment fatigue in breast cancer survivors (Curran, Beacham, & Andrykowski, 2004), intimacy and well-being in couples coping with breast cancer (Otto, Laurenceau, Siegal, & Belcher, 2014), and physical activity in survivors of endometrial cancer (Basen-Engquist et al., 2011). These may be important methodological considerations for future studies.

A second possible explanation for the lack of predictive validity of the model is that while seeking advice and body checking are conceptually related and important, they may not be specific consequences of FCR. Indeed, the temporal and progressive relationship of each of the components of the Lee-Jones model was not assessed in this study, and therefore it is unknown as to which factors precede or follow others in the model. Given the scarcity of longitudinal research on FCR, it is difficult to determine true "consequences" of FCR, in the sense that they are an effect or a result of FCR. Cross-sectional studies have only identified correlates of FCR, indicating that it is associated with lower quality of life (Simard & Savard , 2013; van den Beuken-van Everdingen et al., 2008), greater health care utilization (Lebel, Tomei, Feldstain, Beattie, & McCallum), anxiety (Dinkel, Kremsreiter, Marten-Mittag, &Lahmann, 2014), depressive symptoms (Sarkar et al., 2014), and intrusive thoughts (Dunn et al., 2015, Simard, Savard, & Ivers, 2010). Examination of the cause and effect with regards to these correlates is an important future direction for research and early intervention in this area.

Clinical Implications

Implications for healthcare professionals. The results of this study suggest that FCR is a critical target for optimal care of ovarian cancer patients. Data from the current research as well as prior studies stress the importance of training healthcare professionals to identify survivors who may require assistance in coping with FCR. Healthcare providers, including oncologists, would benefit from incorporating assessment and screening for FCR into routine clinical practice with ovarian cancer patients. Recent research has found that the severity subscale of the FCRI allows rapid and effective screening of clinical levels of FCR (Simard & Sivard, 2015). The average FCR score of the current sample was above the clinical threshold for severity (Simard & Savard, 2015), suggesting that a large proportion of ovarian cancer patients in other settings may also endorse severe FCR if given this measure. Given the current scarcity and resource-intensive nature of the available interventions for FCR, it might be useful to implement a triage system. For example, patients with severe FCR upon screening may benefit from further assessment to determine need for intervention. When FCR is identified as impairing social, emotional or occupational functioning, consideration should be given to referring the patient a psychological intervention (Heinrichs, 2012, Herschbach et al., 2010; Lengacher, 2011; Shields, 2010). Although busy clinicians struggle within increasingly contracted timeframes to address their patients' physical and psychosocial conditions, quality cancer care nevertheless requires that it be customized to patients' needs and values and proactive to patients' anticipated needs (Adler & Page, 2008). The investment in monitoring and early intervention for these women is likely worthwhile in the long run, as severe FCR tends to remain stable throughout treatment and follow-up (Burstein, Gelber, Guadagnoli, & Weeks, 1999; Costanzo et al., 2007; Savard & Ivers, 2013; Stanton, Danoff-Burg, & Huggins, 2002). Furthermore, the results of this study suggest that women at any stage of

disease and at all stages of treatment experience FCR, and it was found to be stable across a three-month period. Taken together, the findings from the current study and other longitudinal data suggest that screening for FCR would beneficial across the cancer experience.

This study highlights the integral role that physical symptoms and somatic stimuli play in the experience of FCR. Healthcare providers would benefit from providing tailored and correct information about one's disease status and education about signs and symptoms of recurrence, as well as how to differentiate benign from worrisome symptoms. Additionally, findings suggest that follow-up medical appointments are not only highly distressing for patients at all stages of disease and treatment, they are an important component of the FCR emotional experience. Healthcare providers should acknowledge and validate this for patients at each visit.

Implications for psychological interventions. Despite a growing number of psychosocial cancer intervention studies, this body of research has evaluated group therapies designed to improve general psychological wellbeing outcomes for breast cancer survivors, and reported on FCR only as a secondary outcome. For example, Lengacher et al. (2014) conducted a randomized controlled trial of a six-week mindfulness based stress reduction intervention and evaluated FCR as a mediator of psychological and physical symptoms. Participants who received the intervention demonstrated a significant reduction in FCR concerns (Lengacher et al., 2014). Herschbach et al. (2010) reported on the effects of general group CBT compared to nondirective group supportive experiential therapy (SET) with a sample of patients with chronic arthritis or cancer and compared them to a control group recruited one year later. Findings showed that fear of illness progression decreased in both the CBT and SET intervention groups, as compared to the control group (Herschbach et al., 2010). These studies have several noteworthy limitations, including the almost exclusive examination of the interventions on breast cancer patients, the use

of FCR as a secondary outcome, and the lack of theoretical foundation guiding the intervention. As the field continues to highlight the importance of developing empirically validated interventions, more recent interventions have heeded this cry and created theoretically-based manualized interventions that are designed to specifically target FCR in cancer survivors.

Most recent, are published results from a multi-site, randomized trial of 221 cancer survivors, known as the ConquerFear study (Butow et al., 2017). The ConquerFear is a theoretically based, manualized intervention predominantly based on the CSM (Leventhal et al., 1980). The key goals of the ConquerFear intervention are: to teach strategies for controlling worry and excessive threat monitoring, modify unhelpful beliefs about worry, develop appropriate monitoring and screening behaviours, educate about follow-up and strategies to reduce risk of recurrence (e.g., exercising), address existential issues, and promote goal setting. Butow et al. (2017) evaluated the efficacy of ConquerFear in disease-free breast cancer, colorectal cancer and melanoma survivors with clinical FCR levels, as defined by a score of 13 or higher on the FCRI severity subscale (Simard & Sivard, 2015) compared with a non-specific attention control intervention with immediate as well as 3- and 6-month post-treatment outcome data. Results suggested that compared to the control treatment group, those randomized to the ConquerFear intervention had clinically and statistically improved overall FCR scores, which were maintained six months post-intervention. Importantly, the participants in this study were disease-free at the time of the intervention, and all likely had differing prognoses, which are two significant factors that may limit the generalizability of these findings to an ovarian cancer population.

In addition to ConquerFear, the fear of recurrence therapy (FORT) intervention (Maheu et al., 2016) is also predominantly theoretically guided by Leventhal's CSM (Leventhal et al., 1980). The results of a recent RCT have yet to be published (Maheu, 2016), however data from a pilot

feasibility study demonstrated that this brief, 6-week, group intervention may be successful in decreasing FCR among women with breast and ovarian cancer, with improvements maintained at 3 months (Lebel et al., 2014). The key goals of FORT are to: distinguish worrisome symptoms from benign ones; identify FCR triggers and inappropriate coping strategies; facilitate the learning and use of new coping strategies, such as relaxation techniques and cognitive restructuring; increase tolerance for uncertainty; promote emotional expression of specific fears that underlie FCR; and re-examine life priorities and set realistic goals for the future.

Given the theoretical foundation of FORT, a major focus is cognitive restructuring, particularly targeting perceived risk, as this is believed to be the link between triggers (internal and external) and FCR, and subsequent maladaptive coping responses. The data from the current study do not support this link, demonstrating that it is the emotional experience of FCR that influences behavioural responses, not perceived risk. One possible reason why our data may not support this theoretical assumption is that there are significant differences in the samples. Despite reporting that the study population of the pilot study was women with breast and gynaecological cancers, it is important to note that 82.1% of the sample had breast cancer, while only 17.9% carried a diagnosis of ovarian cancer, suggesting that the results may be more representative of a breast cancer population. A second possible reason is the significant difference between being disease-free compared to ovarian cancer, in which one is never truly disease-free. Participants in the FORT study were limited to being in stage 0-3 and were required to be disease-free at the start of the group. Data were not used in the final analyses if a participant experienced a cancer recurrence. Consequently, it is unclear how generalizable the results of this pilot study are to ovarian cancer patients, given the high percentage of patients who are diagnosed at late stage and the rate of recurrence. Indeed, given these exclusion criteria,

a large portion of our sample would not have been eligible to participate in this treatment study. Therefore, a specific focus on perceived risk may be a relevant and beneficial target for women who are disease-free with a promising prognosis, however may not be as pertinent for women with a less nuanced course of disease with less favourable prognosis.

While these treatments appear promising, their basis in CSM may reduce the applicability of certain components of the treatment to ovarian cancer, particularly late stage patients. For example, learning strategies to reduce recurrence, such as exercising, may not be relevant or helpful in a population with such a high likelihood of recurrence, and may introduce beliefs of controllability that are unfounded. However, many of the components of the ConquerFear and FORT studies are compatible with our findings, including distinguishing worrisome symptoms from benign ones, developing appropriate monitoring and screening behaviours, and addressing unhelpful thoughts related to worrying. Given that many interventions are predominantly based on Leventhal's CSM (1980), it may be worthwhile for future research to compare Lee-Jones et al.'s (1997) cognitive model to the CSM model in a single study. This may serve to inform which model is a better fit, and highlight important similarities and differences, which could be beneficial for the continued development and refinement of evidence-based interventions specifically designed to target FCR.

The current study highlights the significance of the emotional experience in FCR for women with ovarian cancer, and is in line with the conceptual background underlying Barlow and colleagues' Unified Protocol for Transdiagnostic Treatment of Emotional Disorders (UP; Barlow et al., 2004; Barlow et al., 2010; Boisseau et al., 2010; Wilamowska et al., 2010). This is not in any way meant to suggest that FCR is an emotional disorder, rather that several components from this treatment may be highly applicable to this population. Consistent with the existing interventions for FCR, the UP has its roots in cognitive behavioural principles, but is

unique in the particular emphasis placed on the way individuals experience and respond to their emotions. By focusing on the patient's particular emotional experience, the UP emphasizes the adaptive functional nature of emotions, and seeks to identify and correct maladaptive attempts to regulate emotional experiences (Barlow et al., 2010). Based on the findings from this study, several modules from this protocol appear may be particularly relevant for women with ovarian cancer who are struggling with FCR.

Specifically, and in line with the protocol, patients may benefit from learning about the adaptive nature of emotions and identifying the main components of an emotional experience (physiological, cognitive, and behavioural), with a specific focus on why the full range of negative and positive emotions are both necessary and functional. An appreciation for the function of emotions is intended to reduce one's aversion to experiencing negative emotions, which in turn reduces its intensity. Additionally, the concept of Emotion Driven Behaviours (EDBs) (i.e., action tendencies or motivated behavioural responses) from the UP may be particularly relevant for women with ovarian cancer, as demonstrated by the results of this study. Patients may benefit from monitoring their emotional experiences, including identifying antecedents; cognitive, behavioural, and physiological responses; and the short- and long-term consequences of these responses. By fostering a greater acceptance of the adaptive, functional nature of emotions, and helping patients increase their awareness of their own patterns of emotional responding, this may help increase tolerance for the negative and difficult emotions that are inherent in the process of facing a life threatening illness.

Additionally and consistent with the results from this study, the UP contains emotion awareness training, which focuses on helping patients develop a greater objective awareness of their emotional experiences by monitoring the interaction between thoughts, feelings and

behaviours while anchoring this awareness within the current context in which the emotions occur. This may be particularly relevant for ovarian cancer patients whose present moment experiences may be clouded by past experiences, such as receiving news of a recurrence, or potential upcoming stressors, such as follow up appointments.

The findings from the current study also highlight the important role that physical symptoms play in FCR. In line with components of both the ConquerFear and FORT interventions, patients with ovarian cancer may additionally benefit from help distinguishing worrisome symptoms from benign ones. This may involve supporting the patient in obtaining this information from their medical team, and helping them to utilize this information as appropriately as possible. This may also include cognitive reappraisal strategies should it seem that the patient may be misinterpreting internal cues based on this information, or may address catastrophizing and assist patients to cope with their anxiety as they await a follow-up medical appointments. As is common in a cognitive behavioural approach, cognitive reappraisal strategies help patients develop an understanding of how they interpret or appraise situations and how their appraisals influence patterns of emotional responding, with an emphasis on the ways in which cognitions interact with behaviours and physiological sensations in ongoing emotional experiences. This may help patients with ovarian cancer to foster more flexible thinking as they learn to generate alternative attributions and appraisals when possible, when faced with intense emotional experiences.

Overall, based on the current study's findings, the UP's central focus on helping patients to accept the emotional experiences and teaching them strategies for navigating these experiences in the most adaptive way possible seems highly applicable in helping women with ovarian cancer who are struggling with FCR. As such, tailoring the components outlined above may be beneficial when considering psychological intervention for these clients.

Limitations

The present study is limited by a low response rate of 52.8% at Time 1 and 38.6% at Time 2, which may limit generalizability to the ovarian cancer population. However, this is comparable to the response rate of 38% demonstrated in the recent study on FCR by Custers and colleagues (2017). The present sample may represent healthier patients and more highly educated participants than the general population (Reisine, Fifield, & Winkelman, 2000). This is consistent with prior research on socioeconomic and ethnic disparities in quality of life in a cohort of breast cancer survivors, which found that non-responders were significantly more likely to have lower educational attainment, and to be diagnosed at a more advanced breast cancer stage (Bowen et al., 2007). Although data on non-responders was not collected in the current study, anecdotal information gathered throughout the recruitment process suggest that those who did not participate in the study were more ill. Indeed, one of the most frequent reasons patients who were approached provided when they declined participation was that they were too sick to complete the study questionnaire. As such, had the response rate been 100%, it would have likely resulted in a sample of women who were even sicker, and likely more distressed. Alternatively, there could be a self-selection bias wherein those who completed the measures were patients whom FCR was particularly relevant. This may be confirmed by the high percentage of patients with clinically elevated levels of FCR in the sample. Selection bias is an aspect that should be taken into account when designing research on FCR since a proportion of survivors recognize their FCR and express a need for help whereas other survivors cope with FCR by avoiding threat, including study questionnaires (Custers et al., 2017). Of note, we did not find significant medical differences between participants who only completed the Time 1

questionnaire compared to participants who completed both time points, but selection bias should be considered for those who did or did not agree to participate in the study.

Several sociodemographic and medical limitations are important to note. First, the sample was highly educated and predominantly Caucasian, which may limit its generalizability. Second, additional potentially clinical and medically relevant information was overlooked. When participants were asked about current treatment, one of the options was "no current treatment." Unfortunately, participants were not prompted to specify whether they were not receiving treatment because they were in remission or because they were in palliative care. In addition, information about participation in clinical treatment trials was not collected. Given that Princess Margaret Hospital is a large research and training institute, it is possible that a large portion of the sample was involved in a clinical trial. Having this information would have enriched the clinical picture of the present, particularly as it relates to their treatment experience and prognosis.

There were several limitations related to the measures used in the study. The use of single items derived from subscales of the FCRI with unknown psychometric properties introduces the possibility of poor construct validity, meaning what is intended to be measured may not be what is actually assessed. Given the shortage of well-measured constructs in this area, researchers are continuing to use single-item scales. For example, Custers and colleagues (2017) also used single items from this scale in their recent study of FCR. Additionally, certain items such as knowledge about cancer and prior cancer diagnosis were created for the current study, and several scales were revised to improve reliability, and therefore the psychometric properties of these measures have not been established, which may impact validity. These measures merit more psychometric study with ovarian cancer patients, however these revised scales offer a potential revised version for future research. Furthermore, as this is the first study to evaluate the components proposed by the

cognitive model, the most appropriate measures available were selected, however they may not have accurately assess the intended components and further evaluation is warranted. It is noteworthy that the Cronbach's alpha of two of the study measures, seeking advice and misinterpretation of symptoms, produced unacceptable and questionable values. Given that the coefficient alpha has been demonstrated to be inappropriate for two-item scales (Eisinga, te Grontenhuis, & Pelzer, 2012), the inter-item correlation was calculated as recommended, and these values for these measures were well within the acceptable range (Clark & Watson, 1995). These scales would benefit from additional psychometric evaluation in future research

Another potential limitation of the current research is the design; specifically timeline regarding follow-up and the correlational nature of the data. First, it is possible that three months may not have been sufficient time to assess the stability of the model, while it may also have been too lengthy of an interval to accurately capture the predictive validity of the model. Future research may benefit from including several time points for follow-up in order to increase the likelihood that these outcomes are assessed in a timely manner, or incorporating ecological momentary assessment (e.g., daily diaries) into their assessment protocol. In addition, the correlational study design makes it difficult to draw conclusions about causality. Although directional relationships were tested, conclusions about causation cannot be inferred. Future research should focus on the direction of the relationships and the possibility of bidirectional relationships within the model to further strengthen our theoretical knowledge of FCR.

Despite these limitations, the current study makes several important contributions to the literature. This is the first study to comprehensively test and demonstrate good fit of the cognitive model of FCR put forth by Lee-Jones and colleagues (1997) in an ovarian cancer population. Given the extremely high rate of recurrence in ovarian cancer and the associated

poor prognosis, an increased understanding of the unique way that this population experiences FCR is necessary to guide clinical intervention targeted to their specific needs. This study also contributes much needed longitudinal data regarding the stability of FCR across time, suggesting that these components are largely stable across a three-month time period, even among women who experience a recurrence.

Appendix 1: Questionnaires

Patient Demographic and Medical Questionnaire

Study ID _____

Understanding the Psychological Well-Being of Individuals and Couples Facing Ovarian Cancer

Today's Date: _____

1) Age: _____

2) With whom do you live? ☐ Spouse/Partner ☐ Self ☐ Children ☐

Other_____

3) Relationship Status: ☐ Married/Partnered ☐ Separated ☐ Divorced ☐ Widowed ☐ Single

☐ Other_____

4) If you are in a relationship, how long have you been with your spouse/partner? _____

5) Do you have any biological children? Yes ☐ No ☐

If yes, how many? _____

6) Employment:

Working full-time ☐ Working part-time ☐ Retired ☐ Disability ☐ Not Employed ☐

7) What is/was your job title? _____

8) What is your average annual income?

a) 0-40,000
b) 41,000-75,000
c) ≥75,000
d)

9) Years of education:

a) High School
b) Some College/University
c) College/University degree
d) Graduate School
e)

10) Ethnicity:

☐ White ☐ Black ☐ Aboriginal/Native/Indigenous

☐ Asian ☐ Hispanic ☐ Other _____

Treatment-Related Information

Date of first ovarian cancer diagnosis _____

What is the stage of your ovarian cancer?

- ☐ Stage 1
- ☐ Stage 2
- ☐ Stage 3
- ☐ Stage 4
- ☐ Other _____(please specify)

Type of treatment at current time:

- ☐ Surgery only
- ☐ Chemotherapy only
- ☐ Surgery and chemotherapy
- ☐ Radiation therapy only
- ☐ Surgery and Radiation therapy
- ☐ Surgery, Radiation, and Chemotherapy
- ☐ Nor currently receiving treatment

PAST Type of treatment (not at the current time, but you have received in the past):

- ☐ Surgery only
- ☐ Chemotherapy only
- ☐ Surgery and chemotherapy
- ☐ Radiation therapy only
- ☐ Surgery and Radiation therapy
- ☐ Surgery, Radiation, and Chemotherapy
- ☐ Not applicable

At what point in your treatment are you at the current time? (check one)

☐ At time of initial diagnosis

☐ During primary treatment of ovarian cancer (i.e., surgery/chemotherapy)

☐ Within 6 months of completing your first treatment

☐ Within 6 to 12 months of completing your first treatment

☐ Greater than one year from completing your first treatment

☐ After recurrence of cancer

☐ Other (please specify)_____

Have you ever received genetic testing to see if you have a mutation on the BRCA gene?

☐ Yes ☐ No

If you have received testing, did you receive a positive test result for:

BRCA 1 ☐ Yes ☐ No

BRCA 2 ☐ Yes ☐ No

15) Please provide the following information about your cancer experience, including recurrences:

Type of Cancer You Were Diagnosed With (including recurrences)	Age of Diagnosis	Date of Diagnosis	Type of Treatment Received
1.			
2.			
3.			
4.			
5.			

16) Has your mother ever been diagnosed with ANY type of cancer? □ Yes □ No

If yes, please answer the following:

Type(s) of Cancer Diagnosed With	When was the diagnosis?
1.	
2.	
3.	
4.	
5.	

17) Has your father ever been diagnosed with ANY type of cancer? □ Yes □ No

If yes, please answer the following:

Type(s) of Cancer Diagnosed With	When was the diagnosis?
1.	
2.	
3.	
4.	
5.	

19) Has a sibling ever been diagnosed with ANY type of cancer? □ Yes □ No

If yes, please answer the following:

	Type(s) of Cancer Diagnosed With	When was the diagnosis?
Sibling 1		
Sibling 2		
Sibling 3		
Sibling 4		
Sibling 5		
Sibling 6		

20) Has your child ever been diagnosed with ANY type of cancer? □ Yes □ No

If yes, please answer the following:

	Type(s) of Cancer Diagnosed With	When was the diagnosis?

Child 1		
Child 2		
Child 3		
Child 4		
Child 5		

Treatment-Related Information TIME 2

Has your ovarian cancer recurred (that is, come back or returned after being in remission) since completing the last survey (in the last 3 months)?

☐Yes ☐ No

If yes, what date was the recurrence diagnosed? _____

Type of treatment at current time:

- ☐ Surgery only
- ☐ Chemotherapy only
- ☐ Surgery and chemotherapy
- ☐ Radiation therapy only
- ☐ Surgery and Radiation therapy
- ☐ Surgery, Radiation, and Chemotherapy
- ☐ Not currently receiving treatment

If you are not currently receiving treatment, what treatment did you receive for your recurrence?

- ☐ Surgery only
- ☐ Chemotherapy only
- ☐ Surgery and chemotherapy
- ☐ Radiation therapy only
- ☐ Surgery and Radiation therapy
- ☐ Surgery, Radiation, and Chemotherapy
- ☐ No treatment

At what point in your treatment are you at the current time? (check one)

☐ At time of recurrence diagnosis

☐ During primary treatment of ovarian cancer (i.e., surgery/chemotherapy)

☐ Within 6 months of completing your first treatment

☐ Within 6 to 12 months of completing your first treatment

☐ Greater than one year from completing your first treatment

☐ Receiving treatment for recurrence

☐ Other (please specify)_____

Fear of Cancer Recurrence Inventory

Most people who have been diagnosed with cancer are worried, to varying degrees, that there might be a recurrence of the cancer. **By recurrence, we mean the possibility that the cancer could return or progress in the same place or in another part of the body.** This questionnaire aims to better understand the experience of worries about cancer recurrence. Please read each statement and indicate to what degree it applied to you **DURING THE PAST MONTH** by circling the appropriate number.

0 Never	**1** Rarely	**2** Sometimes	**3** Most of the time	**4** All the time

The following situations make me think about the possibility of cancer recurrence:

1.	Television shows or newspaper articles about cancer or illness ……..	0	1	2	3	4
2.	An appointment with my doctor or other health professional ……..…	0	1	2	3	4
3.	Medical examinations (e.g. annual check-up, blood tests, X-rays) ……..	0	1	2	3	4
4.	Conversations about cancer or illness in general ……..	0	1	2	3	4
5.	Seeing or hearing about someone who is ill ……..	0	1	2	3	4
6.	Going to a funeral or reading the obituary section of the paper ……	0	1	2	3	4
7.	When I feel unwell physically or when I am sick ……..……..	0	1	2	3	4
8.	Generally, I avoid situations or things that make me think about the possibility of cancer recurrence ……..	0	1	2	3	4

0 Not at all	**1** A little	**2** Somewhat	**3** A lot	**4** A great deal

9.	I am worried or anxious about the possibility of cancer recurrence …….	0	1	2	3	4
10.	I am afraid of cancer recurrence ……	0	1	2	3	4
11.	I believe it is normal to be worried or anxious about the possibility of cancer recurrence …..	0	1	2	3	4
12.	When I think about the possibility of cancer recurrence, this triggers other unpleasant thoughts or images (such as death, suffering, the consequences for my family) ……..	0	1	2	3	4
13.	I believe that I am cured and that the cancer will not come back …….	0	1	2	3	4

14. In your opinion, are you at risk of having a cancer recurrence?

0 Not at all at risk	**1** A little at risk	**2** Somewhat at risk	**3** A lot at risk	**4** A great deal at risk

15. How often do you think about the possibility of cancer recurrence?

0 Never	**1** A few times a month	**2** A few times a week	**3** A few times a day	**4** Several times a day

16. How much time per day do you spend thinking about the possibility of cancer recurrence?

0 I don't think about it	**1** A few seconds	**2** A few minutes	**3** A few hours	**4** Several hours

17. How long have you been thinking about the possibility of cancer recurrence?

0 I don't think about it	**1** A few weeks	**2** A few months	**3** A few years	**4** Several years

0 Not at all	1 A little	2 Somewhat	3 A lot	4 A great deal

When I think about the possibility of cancer recurrence, I feel:

18.	Worry, fear or anxiety ……...	0	1	2	3	4
19.	Sadness, discouragement or disappointment …….	0	1	2	3	4
20.	Frustration, anger or outrage …….	0	1	2	3	4
21.	Helplessness or resignation ……...	0	1	2	3	4

My thoughts or fears about the possibility of cancer recurrence disrupt:

22.	My social or leisure activities (e.g. outings, sports, travel) ……...	0	1	2	3	4
23.	My work or everyday activities …….	0	1	2	3	4
24.	My relationships with my partner, my family, or those close to me …….	0	1	2	3	4
25.	My ability to make future plans or set life goals ……...	0	1	2	3	4
26.	My state of mind or my mood ……...	0	1	2	3	4
27.	My quality of life in general ……...	0	1	2	3	4

0 Not at all	1 A little	2 Somewhat	3 A lot	4 A great deal

28.	I feel that I worry excessively about the possibility of cancer recurrence ……	0	1	2	3	4
29.	Other people think that I worry excessively about the possibility of cancer recurrence ……..	0	1	2	3	4
30.	I think that I worry more about the possibility of cancer recurrence than other people who have been diagnosed with cancer ……..…...	0	1	2	3	4

0 Never	1 Rarely	2 Sometimes	3 Most of the time	4 All the time

When I think about the possibility of cancer recurrence, I use the following strategies to reassure myself:

31.	I call my doctor or other health professional ……...……	0	1	2	3	4
32.	I go to the hospital or clinic for an examination ……...	0	1	2	3	4
33.	I examine myself to see if I have any physical signs of cancer ……	0	1	2	3	4
34.	I try to distract myself (e.g. do various activities, watch television, read, work) …….	0	1	2	3	4
35.	I try not to think about it, to get the idea out of my mind …….	0	1	2	3	4
36.	I pray, meditate or do relaxation ……...	0	1	2	3	4
37.	I try to convince myself that everything will be fine or I think positively ……	0	1	2	3	4
38.	I talk to someone about it ……..	0	1	2	3	4
39.	I try to understand what is happening and deal with it …….	0	1	2	3	4
40.	I try to find a solution ……	0	1	2	3	4
41.	I try to replace this thought with a more pleasant one ……..……	0	1	2	3	4
42.	I tell myself “stop it” …….	0	1	2	3	4
	Do you feel reassured when you use these strategies? …….	0	1	2	3	4

ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

***Name*……** ***Date*……**

YOUR VIEWS ABOUT YOUR ILLNESS

Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

	I have experienced this symptom *since my illness*			**This symptom is *related to my illness***	
Pain	**Yes**	**No**	_____	**Yes**	**No**
Sore Throat	**Yes**	**No**	_____	**Yes**	**No**
Nausea	**Yes**	**No**	_____	**Yes**	**No**
Breathlessness	**Yes**	**No**	_____	**Yes**	**No**
Weight Loss	**Yes**	**No**	_____	**Yes**	**No**
Fatigue	**Yes**	**No**	_____	**Yes**	**No**
Stiff Joints	**Yes**	**No**	_____	**Yes**	**No**
Sore Eyes	**Yes**	**No**	_____	**Yes**	**No**
Wheeziness	**Yes**	**No**	_____	**Yes**	**No**
Headaches	**Yes**	**No**	_____	**Yes**	**No**
Upset Stomach	**Yes**	**No**	_____	**Yes**	**No**
Sleep Difficulties	**Yes**	**No**	_____	**Yes**	**No**
Dizziness	**Yes**	**No**	_____	**Yes**	**No**
Loss of Strength	**Yes**	**No**	_____	**Yes**	**No**

We are interested in your own personal views of how you now see your current illness.

Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

	VIEWS ABOUT YOUR ILLNESS	**STRONGLY DISAGREE**	**DISAGREE**	**NEITHER AGREE NOR DISAGREE**	**AGREE**	**STRONGLY AGREE**
IP1	**My illness will last a short time**					
IP2	**My illness is likely to be permanent rather than temporary**					
IP3	**My illness will last for a long time**					
IP4	**This illness will pass quickly**					
IP5	**I expect to have this illness for the rest of my life**					
IP6	**My illness is a serious condition**					

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP7	My illness has major consequences on my life					
IP8	My illness does not have much effect on my life					
IP9	My illness strongly affects the way others see me					
IP10	My illness has serious financial consequences					
IP11	My illness causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my illness gets better or worse					
IP14	The course of my illness depends on me					
IP15	Nothing I do will affect my illness					
IP16	I have the power to influence my illness					
IP17	My actions will have no affect on the outcome of my illness					
IP18	My illness will improve in time					
IP19	There is very little that can be done to improve my illness					
IP20	My treatment will be effective in curing my illness					
IP21	The negative effects of my illness can be prevented (avoided) by my treatment					
IP22	My treatment can control my illness					
IP23	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My illness is a mystery to me					
IP26	I don't understand my illness					
IP27	My illness doesn't make any sense to me					
IP28	I have a clear picture or understanding of my condition					
IP29	The symptoms of my illness change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My illness is very unpredictable					
IP32	I go through cycles in which my illness gets better and worse.					
IP33	I get depressed when I think about my illness					
IP34	When I think about my illness I get upset					
IP35	My illness makes me feel angry					
IP36	My illness does not worry me					
IP37	Having this illness makes me feel anxious					
IP38	My illness makes me feel afraid					

CAUSES OF MY ILLNESS

We are interested in what <u>you</u> consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	**Stress or worry**					
C2	**Hereditary - it runs in my family**					
C3	**A Germ or virus**					
C4	**Diet or eating habits**					
C5	**Chance or bad luck**					
C6	**Poor medical care in my past**					
C7	**Pollution in the environment**					
C8	**My own behaviour**					
C9	**My mental attitude e.g. thinking about life negatively**					
C10	**Family problems or worries caused my illness**					
C11	**Overwork**					
C12	**My emotional state e.g. feeling down, lonely, anxious, empty**					
C13	**Ageing**					
C14	**Alcohol**					
C15	**Smoking**					
C16	**Accident or injury**					
C17	**My personality**					
C18	**Altered immunity**					

In the table below, please list in rank-order the three most important factors that you now believe caused <u>YOUR illness.</u> You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-

1. _____
2. _____
3. _____

Openness of Discussion in the Family

1. I talk as little as possible about my illness because I don't want to make my family uneasy.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

2. My partner doesn't like me to talk about my problems.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

3. My children don't like to talk about my problems.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

4. If I talk about my illness, others gloss over it.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

5. My family always wants to hear from me that I am doing well.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

6. Talking about emotions related to my illness upsets my family.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

7. My partner often doesn't know what to say or do when I'm feeling down.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

8. My children often don't know what to say or do when I am feeling down.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

9. I am mostly the one who starts the conversation in the family about my disease and problems.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

Brief Cope_Patient

These items deal with ways you've been coping with the stress in your life since you found out were diagnosed with cancer. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices, and circle the appropriate number. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1. I've been turning to work or other activities to take my mind off things.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

2. I've been concentrating my efforts on doing something about the situation I'm in.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

3. I've been saying to myself "this isn't real."

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

4. I've been using alcohol or other drugs to make myself feel better.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

5. I've been getting emotional support from others.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

6. I've been giving up trying to deal with it.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

7. I've been taking action to try to make the situation better.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

8. I've been refusing to believe that it has happened.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

9. I've been saying things to let my unpleasant feelings escape.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

10. I've been getting help and advice from other people.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

11. I've been using alcohol or other drugs to help me get through it.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

12. I've been trying to see it in a different light, to make it seem more positive.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

13. I've been criticizing myself.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

14. I've been trying to come up with a strategy about what to do.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

15. I've been getting comfort and understanding from someone.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

16. I've been giving up the attempt to cope.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

17. I've been looking for something good in what is happening.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

18. I've been making jokes about it.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

20. I've been accepting the reality of the fact that it has happened.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

21. I've been expressing my negative feelings.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

22. I've been trying to find comfort in my religion or spiritual beliefs.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

23. I've been trying to get advice or help from other people about what to do.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

24. I've been learning to live with it.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

25. I've been thinking hard about what steps to take.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

26. I've been blaming myself for things that happened.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

27. I've been praying or meditating.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

28. I've been making fun of the situation.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

LOT-R

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements. There are no "correct" or "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

A = I agree a lot
B = I agree a little
C = I neither agree nor disagree
D = I DISagree a little
E = I DISagree a lot

Please write the letter that best corresponds with how you feel in each blank space below.

_____ 1. In uncertain times, I usually expect the best.
_____ 2. It's easy for me to relax.
_____ 3. If something can go wrong for me, it will.
_____ 4. I'm always optimistic about my future.
_____ 5. I enjoy my friends a lot.
_____ 6. It's important for me to keep busy.
_____ 7. I hardly ever expect things to go my way.
_____ 8. I don't get upset too easily.
_____ 9. I rarely count on good things happening to me.
_____ 10. Overall, I expect more good things to happen to me than bad.

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Ovarian Cancer Fear Scale (adapted)

1. The thought of my ovarian cancer scares me

1	2	3	4	5
Strongly	Disagree	Neither agree	Agree	Strongly

2. When I think about my ovarian cancer, I feel nervous

1	2	3	4	5
Strongly	Disagree	Neither agree	Agree	Strongly

3. When I think about ovarian cancer, I get upset

1	2	3	4	5
Strongly	Disagree	Neither agree	Agree	Strongly

4. When I think about ovarian cancer, I get depressed

1	2	3	4	5
Strongly	Disagree	Neither agree	Agree	Strongly

5. When I think about ovarian cancer, I get jittery

1	2	3	4	5
Strongly	Disagree	Neither agree	Agree	Strongly

6. When I think about ovarian cancer, my heart beats faster

1	2	3	4	5
Strongly	Disagree	Neither agree	Agree	Strongly

7. When I think about ovarian cancer, I feel uneasy

1	2	3	4	5
Strongly	Disagree	Neither agree	Agree	Strongly

8. When I think about ovarian cancer, I feel anxious

1	2	3	4	5
Strongly	Disagree	Neither agree	Agree	Strongly

Decision Regret Scale

Please reflect on the first decision that you made about your treatment. Please indicate how strongly you agree or disagree with these statements by circling a number from 1 (strongly agree) to 5 (strongly disagree) which best fits your view about your decision.

It was the right decision for me	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I regret the choice that was made	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
I would go for the same choice if I had to do it over again	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
The choice did me a lot of harm	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
The decision was a wise one	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree

Future- Oriented Planning Scale

Please indicate how much each item described you:

1. I like to make plans for the future.

1	2	3	4
A lot	Some	A little	Not at all

2. I find it helpful to set goals for the near future.

1	2	3	4
A lot	Some	A little	Not at all

3. I live one day at a time.

1	2	3	4
A lot	Some	A little	Not at all

4. I have too many things to think about today to think about tomorrow.

1	2	3	4
A lot	Some	A little	Not at all

5. I believe there is no sense planning too far ahead because so many things can change.

1	2	3	4
A lot	Some	A little	Not at all

Short Health Anxiety Inventory

Each question in this section consists of a group of four statements. Please read each group of statements carefully and then select the one which best describes your feelings **over the past six months**. Identify the statement by circling the letter next to it. For instance, if you think that statement (a) is correct, circle statement (a); it may be that more than one statement applies, in which case, please circle any that are applicable.

HAI1) (a) I do not worry about my health.
(b) I occasionally worry about my health.
(c) I spend much of my time worrying about my health.
(d) I spend most of my time worrying about my health.

HAI2) (a) I notice aches and pains less than most other people (of my age).
(b) I notice aches and pains as much as most other people (of my age).
(c) I notice aches and pains more than most other people (of my age).
(d) I am aware of aches and pains in my body all the time.

HAI3) (a) As a rule I am not aware of bodily sensations or changes.
(b) Sometimes I am aware of bodily sensations or changes.
(c) I am often aware of bodily sensations or changes.
(d) I am constantly aware of bodily sensations or changes.

HAI4) (a) Resisting thoughts of illness is never a problem.
(b) Most of the time I can resist thoughts of illness.
(c) I try to resist thoughts of illness but am often unable to do so.
(d) Thoughts of illness are so strong that I no longer even try to resist them.

HAI5) (a) As a rule I am not afraid that I have a serious illness.
(b) I am sometimes afraid that I have a serious illness.
(c) I am often afraid that I have a serious illness.
(d) I am always afraid that I have a serious illness.

HAI6) (a) I do not have images (mental pictures) of myself being ill.
(b) I occasionally have images of myself being ill.
(c) I frequently have images of myself being ill.
(d) I constantly have images of myself being ill.

HAI7) (a) I do not have any difficulty taking my mind off thoughts about my health.
(b) I sometimes have difficulty taking my mind off thoughts about my health.
(c) I often have difficulty taking my mind off thoughts about my health.
(d) Nothing can take my mind off thoughts about my health.

HAI8) (a) I am lastingly relieved if my doctor tells me there is nothing wrong.
(b) I am initially relieved but the worries sometimes return later.
(c) I am initially relieved but the worries always return later.
(d) I am not relieved if my doctor tells me there is nothing wrong.

HAI9) (a) If I hear about an illness I never think I have it myself.
(b) If I hear about an illness I sometimes think I have it myself.
(c) If I hear about an illness I often think I have it myself.

(d) If I hear about an illness I always think I have it myself.

HAI10) (a) If I have a bodily sensation or change I rarely wonder what it means.
(b) If I have a bodily sensation or change I often wonder what it means.
(c) If I have a bodily sensation or change I always wonder what it means.
(d) If I have a bodily sensation or change I must know what it means.

HAI11) (a) I usually feel at very low risk for developing a serious illness.
(b) I usually feel at fairly low risk for developing a serious illness.
(c) I usually feel at moderate risk for developing a serious illness.
(d) I usually feel at high risk for developing a serious illness.

HAI12) (a) I never think I have a serious illness.
(b) I sometimes think I have a serious illness.
(c) I often think I have a serious illness.
(d) I usually think that I am seriously ill.

HAI13) (a) If I notice an unexplained bodily sensation I don't find it difficult to think about other things.
(b) If I notice an unexplained bodily sensation I sometimes find it difficult to think about other things
(c) If I notice an unexplained bodily sensation I often find it difficult to think about other things.
(d) If I notice an unexplained bodily sensation I always find it difficult to think about other things.

HAI14) (a) My family friends would say I do not worry enough about my health.
(b) My family friends would say I have a normal attitude to my health.
(c) My family friends would say I worry too much about my health.
(d) My family friends would say I am a hypochondriac.

HAI15) (a) If I had a serious illness I would still be able to enjoy things in my life quite a lot.
(b) If I had a serious illness I would still be able to enjoy things in my life a little.
(c) If I had a serious illness I would be almost completely unable to enjoy things in my life.
(d) If I had a serious illness I would be completely unable to enjoy life at all.

HAI16) (a) If I developed a serious illness, there is a good chance that modern medicine would be able to cure me
(b) If I developed a serious illness, there is a moderate chance that modern medicine would be able to cure me.
(c) If I developed a serious illness, there is a very small chance that modern medicine would be able to cure me.
(d) If I developed a serious illness, there is no chance that modern medicine would be able to cure me.

HAI17) (a) A serious illness would ruin some aspects of my life.
(b) A serious illness would ruin many aspects of my life.
(c) A serious illness would ruin almost every aspect of my life.
(d) A serious illness would ruin every aspect of my life.

HAI18) (a) If I had a serious illness I would not feel that I had lost my dignity.
(b) If I had a serious illness I would feel that I had lost a little of my dignity.
(c) If I had a serious illness I would feel that I had lost quite a lot of my dignity.

(d) If I had a serious illness I would feel that I had totally lost my dignity.

State Trait Anxiety Inventory

Read each statement and select the appropriate response to indicate how you feel right now, that is, at this very moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	1	**2**	**3**	**4**
	Not at all	**A little**	**Somewhat**	**Very Much So**
1.	I feel calm	1	2	3	4
2.	I feel secure	1	2	3	4
3.	I feel tense	1	2	3	4
4.	I feel strained	1	2	3	4
5.	I feel at ease	1	2	3	4
6.	I feel upset	1	2	3	4
7.	I am presently worrying over possible misfortunes	1	2	3	4
8.	I feel satisfied	1	2	3	4
9.	I feel frightened	1	2	3	4
10.	I feel uncomfortable	1	2	3	4
11.	I feel self confident	1	2	3	4
12.	I feel nervous	1	2	3	4
13.	I feel jittery	1	2	3	4
14.	I feel indecisive	1	2	3	4
15.	I am relaxed	1	2	3	4
16.	I feel content	1	2	3	4
17.	I am worried	1	2	3	4
18.	I feel confused	1	2	3	4
19.	I feel steady	1	2	3	4
20.	I feel pleasant	1	2	3	4

Name:_____ Date:_____

Panic Disorder Severity Scale – Self Report Form

Several of the following questions refer to panic attacks and limited symptom attacks. For this questionnaire we define a panic attack as a sudden rush of fear or discomfort accompanied by at least 4 of the symptoms listed below. In order to qualify as a sudden rush, the symptoms must peak within 10 minutes. Episodes like panic attacks but having fewer than 4 of the listed symptoms are called limited symptom attacks. Here are the symptoms to count:

- Rapid or pounding heartbeat
- Sweating
- Trembling or shaking
- Breathlessness
- Feeling of choking
- Chest pain or discomfort
- Nausea
- Dizziness or faintness
- Feelings of unreality
- Numbness or tingling
- Chills or hot flushes
- Fear of losing control or going crazy
- Fear of dying

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1. How many panic and limited symptoms attacks did you have during the week?

   0 No panic or limited symptom episodes
   1 Mild: no full panic attacks and no more than 1 limited symptom attack/day
   2 Moderate: 1 or 2 full panic attacks and/or multiple limited symptom attacks/day
   3 Severe: more than 2 full attacks but not more than 1/day on average
   4 Extreme: full panic attacks occurred more than once a day, more days than not

2. If you had any panic attacks during the past week, how distressing (uncomfortable, frightening) were they while they were happening? (If you had more than one, give an average rating. If you didn't have any panic attacks but did have limited symptom attacks, answer for the limited symptom attacks.)

   0 Not at all distressing, or no panic or limited symptom attacks during the past week
   1 Mildly distressing (not too intense)
   2 Moderately distressing (intense, but still manageable)
   3 Severely distressing (very intense)
   4 Extremely distressing (extreme distress during all attacks)

3. During the past week, how much have you worried or felt anxious about when your next panic attack would occur or about fears related to the attacks (for example, that they could mean you have physical or mental health problems or could cause you social embarrassment)?

   0 Not at all
   1 Occasionally or only mildly
   2 Frequently or moderately
   3 Very often or to a very disturbing degree
   4 Nearly constantly and to a disabling extent

4. During the past week were there any places or situations (e.g., public transportation, movie theaters, crowds, bridges, tunnels, shopping malls, being alone) you avoided, or felt afraid of (uncomfortable in, wanted to avoid or leave), because of fear of having a panic attack? Are there any other situations that you would have avoided or been afraid of if they had come up during the week, for the same reason? If yes to either question, please rate your level of fear and avoidance this past week.

   0 None: no fear or avoidance
   1 Mild: occasional fear and/or avoidance but I could usually confront or endure the situation. There was little or no modification of my lifestyle due to this.
   2 Moderate: noticeable fear and/or avoidance but still manageable. I avoided some situations, but I could confront them with a companion. There was some modification of my lifestyle because of this, but my overall functioning was not impaired.
   3 Severe: extensive avoidance. Substantial modification of my lifestyle was required to accommodate the avoidance making it difficult to manage usual activities.
   4 Extreme: pervasive disabling fear and/or avoidance. Extensive modification in my lifestyle was required such that important tasks were not performed.

5. During the past week, were there any activities (e.g., physical exertion, sexual relations, taking a hot shower or bath, drinking coffee, watching an exciting or scary movie) that you avoided, or felt afraid of (uncomfortable doing, wanted to avoid or stop), because they caused physical sensations like those you feel during panic attacks or that you were afraid might trigger a panic attack? Are there any other activities that you would have avoided or been afraid of if they had come up during the week for that reason? If yes to either question, please rate your level of fear and avoidance of those activities this past week.

   0 No fear or avoidance of situations or activities because of distressing physical sensations
   1 Mild: occasional fear and/or avoidance, but usually I could confront or endure with little distress activities that cause physical sensations. There was little modification of my lifestyle due to this.
   2 Moderate: noticeable avoidance but still manageable. There was definite, but limited, modification of my lifestyle such that my overall functioning was not impaired.
   3 Severe: extensive avoidance. There was substantial modification of my lifestyle or interference in my functioning.
   4 Extreme: pervasive and disabling avoidance. There was extensive modification in my lifestyle due to this such that important tasks or activities were not performed.

6. During the past week, how much did the above symptoms altogether (panic and limited symptom attacks, worry about attacks, and fear of situations and activities because of attacks) interfere with your ability to work or carry out your responsibilities at home? (If your work or home responsibilities were less than usual this past week, answer how you think you would have done if the responsibilities had been usual.)

   0 No interference with work or home responsibilities
   1 Slight interference with work or home responsibilities, but I could do nearly everything I could if I didn't have these problems.
   2 Significant interference with work or home responsibilities, but I still could manage to do the things I needed to do.
   3 Substantial impairment in work or home responsibilities; there were many important things I couldn't do because of these problems.
   4 Extreme, incapacitating impairment such that I was essentially unable to manage any work or home responsibilities.

7. During the past week, how much did panic and limited symptom attacks, worry about attacks and fear of situations and activities because of attacks interfere with your social life? (If you didn't have many opportunities to socialize this past week, answer how you think you would have done if you did have opportunities.)

   0 No interference
   1 Slight interference with social activities, but I could do nearly everything I could if I didn't have these problems.
   2 Significant interference with social activities but I could manage to do most things if I made the effort.
   3 Substantial impairment in social activities; there are many social things I couldn't do because of these problems.
   4 Extreme, incapacitating impairment, such that there was hardly anything social I could do.

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