


## ORIGINAL ARTICLE

# Are fear of cancer recurrence and fear of progression equivalent constructs?

Daelin Coutts-Bain<sup>1</sup> | Louise Sharpe<sup>1</sup>  | Poorva Pradhan<sup>1</sup> | Hayley Russell<sup>2</sup> | Lauren C. Heathcote<sup>3</sup> | Daniel Costa<sup>1,4</sup> 

<sup>1</sup>The School of Psychology, University of Sydney, Sydney, New South Wales, Australia

<sup>2</sup>Ovarian Cancer Australia, Melbourne, Victoria, Australia

<sup>3</sup>Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK

<sup>4</sup>Pain Management Research Institute, Royal North Shore Hospital, Sydney, New South Wales, Australia

## Correspondence

Louise Sharpe, The School of Psychology, University of Sydney, Sydney, NSW 2006, Australia.

Email: [Louise.sharpe@sydney.edu.au](mailto:Louise.sharpe@sydney.edu.au)

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## Abstract

**Background:** The predominant definition of fear of cancer recurrence (FCR) conflates FCR with fear of progression (FOP). However, this assumption has never been tested. Importantly, if FCR and FOP are distinct and have different predictors, existing interventions for FCR may not be equally effective for survivors who fear progression rather than recurrence of their disease. The present study aimed to determine whether FCR and FOP are empirically equivalent; and whether they are predicted by the same theoretically derived variables.

**Methods:** Three hundred and eleven adults with a history of breast or ovarian cancer were analysed ( $n = 209$ , 67% in remission). Exploratory factor analysis was conducted on the items of the FCR Inventory severity subscale and short-form FOP Questionnaire together. Structural equation modelling was conducted to predict FCR and FOP and determine whether theoretical models accounted equally well for both constructs, and whether models were equally relevant to those with and without current disease.

**Findings:** The factor analysis demonstrated that the FCR Inventory severity subscale and the short-form FOP Questionnaire loaded onto distinct, but related, factors which represented FCR and FOP. Structural modelling indicated that risk perception and bodily threat monitoring were more strongly associated with FCR than FOP. However, both FCR and FOP were associated with metacognitions and intrusions.

**Interpretation:** These findings suggest that whilst FCR and FOP are related with some overlapping predictors, they are not the same construct. Hence, it is necessary to ensure that in clinical practice and research these constructs are considered separately.

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**KEYWORDS**

breast cancer, cancer, cognition, fear of cancer recurrence, fear of progression, intrusions, metacognitions, oncology, ovarian cancer, perceived risk, survivorship

Despite advances in cancer treatment, many cancer survivors are confronted with the possibility that their cancer will return. Fear of cancer recurrence (FCR) is a common experience, with one review indicating approximately 73% of cancer survivors have some degree of FCR, and 49% report moderate to high FCR.<sup>1</sup> Even when the objective risk of recurrence is low, FCR remains stable and high for years after treatment.<sup>1,2</sup> FCR is defined as 'fear, worry or concern relating to the possibility that cancer will come back or progress'<sup>3</sup> and may be adaptive by motivating engagement with positive health behaviours.<sup>4</sup> However, FCR can become highly distressing, chronic, and disabling, and is associated with negative health outcomes including depression and anxiety<sup>1,5,6</sup> and generalised anxiety disorder.<sup>6,7</sup> Multiple reviews identify help with FCR as among the most commonly reported unmet needs of cancer survivors.<sup>1,8,9</sup> In addition, FCR has been found to predict several important health behaviours, including: increased use of psychotherapeutic medication,<sup>10</sup> increased health care use,<sup>10-12</sup> and complementary medicine use, and decreased use of mammograms.<sup>11</sup>

Several models to understand FCR and related anxieties have been developed, for example,<sup>13-16</sup> Further, effective psychological interventions for FCR have been developed and evaluated and have been shown to reduce FCR.<sup>16,17</sup> Such interventions are a cost-effective way to reduce the financial burden of FCR, according to a recent systematic review.<sup>18</sup> However, most psychological interventions for FCR have been evaluated with disease-free, early-stage cancer patients previously treated with curative intent.<sup>17,19-22</sup> Conceptually, FCR seems most relevant to those who have entered remission but fear their cancer returning. Increasingly, those with metastatic cancer are living longer with ongoing active disease, and their fears would logically seem less about cancer returning and more about their fear of the cancer progressing.<sup>1</sup> Additionally, those whose cancer has already recurred cannot, by definition, fear recurrence, although many fear progression. The fact that the literature has not distinguished between those with and without current active disease or whether they fear recurrence and/or progression reflects the consensus definition of FCR, as a fear that 'cancer will come back or progress'.<sup>3</sup> This definition conflates FCR and fear of progression (FOP) and assumes they represent the same latent construct, although this assertion has never been tested.

The current study aims to determine if FCR and FOP are empirically equivalent, as proposed,<sup>3</sup> and whether FCR and FOP can be accounted for by the same theoretical model. We aim to test Fardell et al's cognitive processing model,<sup>13</sup> which suggests that distressing thoughts and emotions are a normal response to cancer. However, when a cancer survivor believes those worries are helpful, harmful or uncontrollable, (i.e., has unhelpful metacognitions), they will experience a cascade of responses marked by worry, rumination,

and bodily threat monitoring that drive FCR-related thoughts.<sup>13</sup> We chose Fardell's model, because there is an evidence-based intervention, ConquerFear,<sup>23</sup> which has been shown to be efficacious, that targets these causal factors. Moreover, reductions in FCR in that study were partially mediated by a decrease in unhelpful metacognitions and intrusive thoughts, confirming their likely role as treatment mechanisms.<sup>24</sup>

This study has two phases. In phase I, we analyse measures of FCR and FOP to explore empirical overlap between the two questionnaires. In phase II, we evaluate the major tenets of the novel cognitive processing model of FCR, to determine whether FCR and FOP can be predicted by the same theoretical model.

## 1 | METHOD

### 1.1 | Participants

Three hundred and fifty-four adults with a diagnosis of breast or ovarian cancer accessed an online survey circulated by Ovarian Cancer Australia (OCA) or Breast Cancer Network Australia (BCNA). Recruitment occurred between the 11th of June and 11th of September 2020. Participants were included in analyses when they provided complete data for phase I ( $n = 304$ ) and phase II ( $n = 278$ ), see Appendix 1.

### 1.2 | Procedure

Participants were recruited via the e-mailing lists of two cancer organisations, namely BCNA and OCA. Additionally, OCA advertised the study on social media. Eligible participants consented and then completed the 20-30-min survey. This study was approved by the University of Sydney's Human Research Ethics Committee.

### 1.3 | Measures

Participants responded to demographic and medical history questions and reported their cancer status in terms of current treatment, and whether they had active disease or were in remission. We were particularly interested in these constructs amongst those with evidence of current disease compared to those without evidence of current disease. All measures possessed high internal consistency (see Appendix 2A for additional descriptive statistics and more information about the scales).

## 1.4 | Fear of cancer recurrence & fear of progression

FCR was assessed with the Fear of Cancer Recurrence Inventory (FCR-I) severity subscale,<sup>5</sup> a validated screening tool for clinical FCR. Higher scores indicate greater FCR and a score  $\geq 22$  indicates clinically significant FCR.<sup>25</sup> FOP was assessed with the short-form Fear of Progression Questionnaire (FoP-Q-SF).<sup>26</sup> The short-form has been validated in cancer samples. Higher scores indicate greater FOP. Scores  $\geq 34$  indicate an elevated degree of FOP, and have been proposed as a marker of clinically significant FOP warranting treatment in clinical trials.<sup>27,28</sup> Both questionnaires were administered to all participants irrespective of disease status. FCRI does instruct participants to interpret FCR as referring to the fear of cancer returning or progressing.

## 1.5 | Intrusive thoughts

Intrusive thoughts about cancer were assessed with the Impact of Event Scale-revised (IES-R) intrusions subscale.<sup>29</sup> This subscale has been validated for assessing intrusive thoughts about cancer in cancer patients.<sup>30</sup> Higher scores indicate greater severity of intrusive thoughts.

## 1.6 | Metacognitions

Metacognitions were assessed with an 18-item subset of the short-form Metacognitions Questionnaire (MCQ-SF).<sup>31</sup> We included the positive beliefs, negative beliefs, and need for control MCQ-SF subscales as these subscales are most often associated with FCR.<sup>32,33</sup> Higher scores indicate more maladaptive metacognitions.

## 1.7 | Body threat monitoring scale (BTMS)

The 19-item Bodily Threat Monitoring Scale (BTMS) was used to assess the degree to which participants monitor their body for signs of a recurrence. Validation of the BTMS is in progress. The items were generated through qualitative interviews with cancer survivors, and the scale has good psychometric properties.<sup>34</sup> Higher scores indicate greater propensity to monitor the body for threatening signs and symptoms (body threat monitoring; BTM).

## 1.8 | Subjective risk perception

Subjective belief in recurrence or progression was assessed with a single item from the short form Concern About Recurrence Questionnaire.<sup>6</sup> Participants indicated their certainty that their cancer would recur or progress on a sliding scale that displayed a value from 0% to 100%.

## 1.9 | Analyses

In phase I, all 21 items from the FCR-I severity subscale and FoP-Q-SF were entered into an exploratory factor analysis (EFA) in SPSS. Factors were extracted using principal axis factoring (PAF) and rotated with the direct oblimin method. The number of factors to extract was determined based on convergence of evidence from scree plot analysis, parallel analysis,<sup>35</sup> and a minimum average partial (MAP) test.<sup>36,37</sup> In phase II, structural equation modelling was conducted in AMOS, where the analytic method was contingent on the results of phase I. Based on the observed results, the core tenets of the novel cognitive processing model were tested by predicting FCR and FOP.

## 2 | RESULTS

### 2.1 | Participant characteristics

Of the 354 participants who accessed the survey, there was a 78.5% completion rate. Little's Missing Completely at Random test demonstrated that data was missing completely at random and not systematically biased ( $\chi^2 = 182.251$ ,  $df = 169$ ,  $p = .230$ ). Analyses were based on 311 people aged between 22 and 81 ( $M = 58.53$ ,  $SD = 11.41$ ). Demographic and medical history frequencies are reported in Table 1.

People with breast and ovarian cancer differed on several medical factors, as would be expected (see supplementary material).

Based on clinical cut-offs for the FCR-I severity subscale, 36.7% a clinical degree of FCR, whereas 42% of participants were in the elevated FOP range. Rates of elevated FOP did not differ by cancer type, but those with ovarian cancer were more likely to be in the clinical FCR range than those with breast cancer. Those with active disease were more likely to have both clinically significant levels of FCR ( $\chi^2 = 30.105$ ,  $df = 1$ ,  $p < 0.001$ ), and elevated FOP ( $\chi^2 = 7.197$ ,  $df = 1$ ,  $p = 0.007$ ). See Appendix 2B for rates of clinical and non-clinical FCR and elevated FOP status.

### 2.2 | Phase I: Exploratory factor analysis

Parallel analysis of the 21 FCR and FOP items based on the 95<sup>th</sup> percentile of random eigenvalues,<sup>35</sup> the MAP test using the original decision-making criteria,<sup>36</sup> and the scree-plot all indicated a two-factor structure. Although the updated MAP test criteria suggested a third factor,<sup>38</sup> convergence of evidence from three of four methods, and lack of a theoretical basis for three factors, suggested a two-factor solution was most appropriate.

A two-factor EFA was conducted using PAF extraction and direct oblimin rotation (Table 2; Figure 1). Cross-loadings were observed for items 1, 2, and 16. However, all other items loaded exclusively with their respective measure. Hence, factor one was comprised largely of FoP-Q-SF items, which loaded positively, and

TABLE 1 Demographics and medical history frequencies

	Full sample N (%)
<b>Marital status</b>	
Never married	51 (16.4)
Married	187 (60.1)
Separated	11 (3.5)
Divorced	47 (15.1)
Widowed	15 (4.8)
<b>Education</b>	
Below highschool	24 (7.7)
Highschool	103 (33.1)
Undergraduate	90 (28.9)
Postgraduate	94 (30.2)
Currently working	136 (43.7)
Children <sup>a</sup>	221 (71.1)
<b>Cancer stage at first diagnosis</b>	
I	84 (27)
II	63 (20.3)
III	106 (34.1)
IV	32 (10.3)
Not known	26 (8.4)
Metastatic disease	84 (27.0)
Past cancer recurrence	81 (26)
Past surgery for cancer	303 (97.4)
<b>Current treatment</b>	
Chemotherapy	46 (14.8)
Radiotherapy	1 (.3)
<b>Other current drugs</b>	
Tamoxifen	17 (5.5)
Other HT <sup>b</sup>	34 (10.9)
Olaparib	14 (4.5)
Other non-HT <sup>b</sup> or unclear	34 (10.9)
<b>Cancer status</b>	
Active	18 (5.8)
In treatment	84 (27)
In remission	209 (67.2)
<b>Cancer type</b>	
Breast	132 (42.4)
Ovarian	179 (57.6)

<sup>a</sup>indicates the participant had at least one child.

<sup>b</sup>HT = hormone therapy. Tamoxifen and Olaparib use were reported separately from other drugs given their high frequency relative to the other reported pharmacotherapies.

factor two was comprised largely of FCR-I severity subscale items, which loaded negatively. This indicates factor one is describing FOP, whilst factor two is describing the negative pole of FCR, that is, no fear of recurrence. These factors accounted for 38.81% and 9.30% of variance respectively, thus 48.11% of variance in participants' response was accounted for. The two factors were negatively correlated ( $r = -.576$ ). In this case, factor 2 describes the negative pole of FCR, thus the finding that factor 1 and 2 are negatively correlated indicates that FCR and FOP are positively associated.

### 2.3 | Phase II: Structural equation modelling

See Figure 2. Bodily threat monitoring significantly predicted FCR but not FOP. Intrusions significantly predicted bodily threat monitoring, FCR, and FOP, intrusions had a significant indirect effect on FCR ( $\beta = 0.038$ ,  $p = 0.004$ ), but not FOP ( $\beta = 0.027$ ,  $p = 0.119$ ), thus threat monitoring partially mediates the effect of intrusions on FCR. Metacognitions significantly predicted bodily threat monitoring and FOP, but not FCR. Since bodily threat monitoring predicts FCR but not FOP, threat monitoring is a full mediator of the effects of metacognitions on FCR ( $\beta = 0.061$ ,  $p = 0.005$ ) but does not mediate the relationship between metacognitions and FOP ( $\beta = 0.044$ ,  $p = 0.132$ ). Risk perception significantly predicted FCR and FOP. Lastly, this model accounted for 40.6% of variance in bodily threat monitoring, 51.9% of variance in FOP, and 59.6% of variance in FCR.

If the direct effects of a variable on FCR and FOP are both significant, differences in the predictive power of either effect can be assessed by checking for overlap in the associated confidence intervals. This is a valid, but conservative, means of identifying a significant difference in effect magnitude.<sup>39</sup> The 95% confidence intervals (CIs) of the direct effect of risk perception on FCR and FOP did not overlap, indicating that risk perception is a stronger predictor of FCR than FOP. All other confidence interval pairs overlapped, indicating that predictors were equally strong for FCR and FOP (Appendix 3).

## 3 | DISCUSSION

Our study is the first to test the prevailing assumption that FCR and FOP represent a single construct. Our results challenged this assumption. The factor analysis demonstrated that items from the FCR-I severity subscale and FoP-Q-SF loaded on separate, albeit related, factors. This confirms that fear of the cancer returning and progressing should not be treated synonymously.

Given that FCR and FOP were highly correlated and predicted by some of the same constructs, one might ask whether the fact that they represent different constructs is important? We would argue that this is crucial to providing optimal care, particularly to

TABLE 2 Results of the EFA of FoP-Q-SF and FCR-I severity subscale items

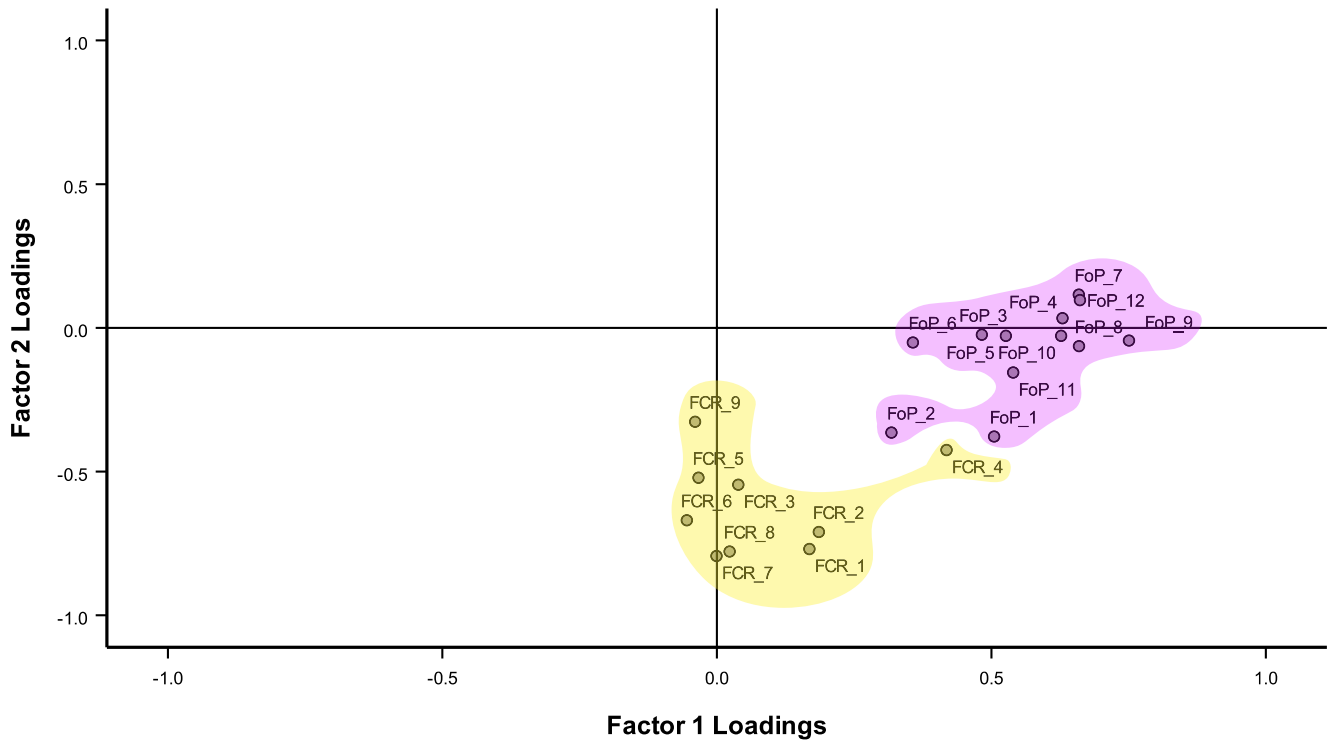
Items	Factor loadings		$h^2$	M	SD
	Factor 1	Factor 2			
1 I Become anxious if I think my disease may progress	<b>·505</b>	<b>−378</b>	·618	3·03	1·10
2 I Am nervous prior to doctors' appointments or periodic examinations	<b>·318</b>	<b>−364</b>	·367	3·45	1·19
3 I Am afraid of pain	<b>·483</b>	−024	·247	2·72	1·02
4 I Have concerns about reaching my professional goals because of my illness	<b>·629</b>	·034	·373	1·98	1·26
5 When I am anxious, I have physical symptoms such as a rapid heartbeat, stomachache or agitation	<b>·526</b>	−028	·295	2·82	1·15
6 The possibility of my children contracting my disease disturbs me	<b>·357</b>	−051	·151	2·30	1·40
7 It disturbs me that I may have to rely on strangers for activities of daily living	<b>·659</b>	·115	·360	2·49	1·28
8 I Am worried that at some point in time I will no longer be able to pursue my hobbies because of my illness	<b>·660</b>	−064	·488	2·56	1·21
9 I Am afraid of severe medical treatments during the course of my illness	<b>·751</b>	−044	·604	2·79	1·19
10 I Worry that my treatment could damage my body	<b>·627</b>	−028	·414	2·91	1·18
11 I Worry about what will become of my family if something should happen to me	<b>·540</b>	−155	·412	3·00	1·32
12 The thought that I might not be able to work due to my illness disturbs me	<b>·661</b>	·096	·373	2·23	1·34
13 I Am worried or anxious about the possibility of cancer recurrence	·168	<b>−769</b>	·769	2·17	1·34
14 I Am afraid of cancer recurrence	·186	<b>−710</b>	·691	2·26	1·18
15 I Think it's normal to be anxious or worried about the possibility of cancer recurrence	·039	<b>−546</b>	·324	2·66	·89
16 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)	<b>·418</b>	<b>−425</b>	·560	2·24	1·23
17 I Believe that I am cured and the cancer will not come back	−034	<b>−521</b>	·253	2·84	1·22
18 In your opinion, are you at risk of having a cancer recurrence?	−055	<b>−669</b>	·409	2·34	1·16
19 How often do you think about the possibility of cancer recurrence?	−001	<b>−794</b>	·629	1·63	1·05
20 How much time per day do you spend thinking about the possibility of cancer recurrence?	·023	<b>−778</b>	·627	1·18	·90
21 How long have you been thinking about the possibility of cancer recurrence?	−040	<b>−327</b>	·093	2·65	1·39

Note: Extraction based on principal axis factoring and direct oblimin rotation. Items 1–12 belong to the FoP-Q-SF, whilst items 13–21 belong to the FCR-I severity subscale. Factor loadings greater than ·30 are bolded. Communalities are indicated by  $h^2$ .  $n = 304$ .

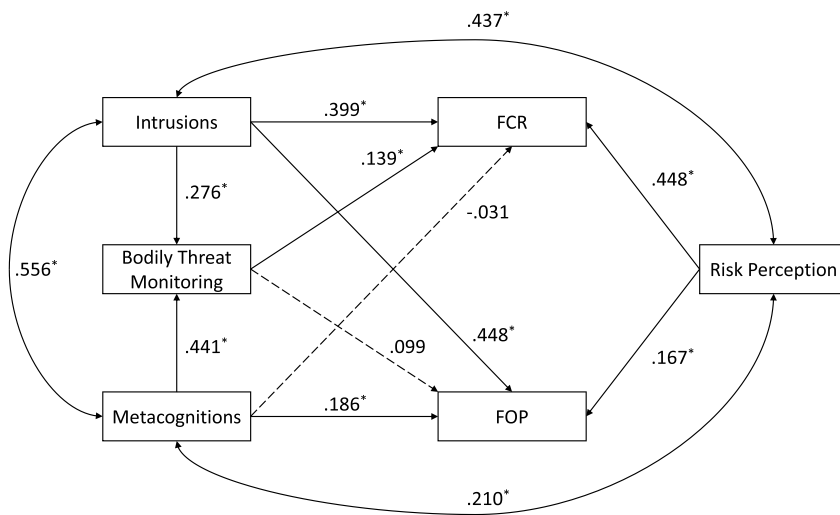
the increasing number of survivors living with advanced disease. To date, the literature has assumed that FOP and FCR are interchangeable and therefore our theoretical understanding of FCR and FOP, as well as our understanding of how to treat these concerns, are built on a conflation of these two constructs. However, in practice, it is fears of progression that are poorly understood. In a 2013 systematic review of quantitative research on FCR included only 18 studies out of 130 (13%) that assessed FOP.<sup>1</sup> Similarly, a meta-analysis of randomised controlled trials for the treatment of FCR included only 3 of 23 (13%) studies which measured FOP as the outcome.<sup>17</sup> Hence, the current literature provides considerably more information about FCR than FOP, particularly in disease-free survivors. As a result, considerably less is known about fears of progression or how to treat them. Given some of the recent advances in personalised medicine, it is likely that an increased number of survivors will present with fears of progression, rather than recurrence.<sup>40</sup> Hence, there is a crucial need to understand the similarities and differences between FCR and FOP.

Our results provide some important information to confirm that the difference between these constructs is not trivial. In relation to FCR, the major tenets of the cognitive processing model were supported. That is, FCR was predicted directly by risk perception, bodily threat monitoring and intrusions. Metacognitions predicted bodily threat monitoring, and was an indirect predictor of FCR severity, as the theory suggests. However, for FOP, the cognitive processing model was only partially supported. That is, both intrusions and metacognitions predicted FOP directly. Risk perception was also associated with FOP, although the relationship was significantly smaller than for FCR, suggesting that high perceived risk does not contribute as much to fears of progression. Another finding was that bodily threat monitoring did not predict FOP, as it did in FCR. This suggests that the degree to which one fears progression of their disease does not predict how vigilant they are towards somatic symptoms, as in FCR.

One speculative account that may explain these findings is that FCR is a form of experiential avoidance. When a cancer survivor



**FIGURE 1** Visual Plot of Factor Loadings in Rotated Factor Space. *Note.* The yellow shading highlights FCR-I severity subscale items, whilst the purple shading highlights FoP-Q-SF items. Each item is numbered according to its order in its respective questionnaire. FoP\_1, FoP\_2, and FCR\_4 were cross-loading items



**FIGURE 2** Combined model predicting FCR and FOP in all participants. *Note.* Straight paths represent standardised regression weights ( $\beta$ ). Curved paths represent correlations. \* $p \leq 0.01$ . Dashed paths are non-significant ( $p > 0.05$ ).  $N = 278$

worries about recurrence, a discrete diagnostic event, they may focus on somatic sensations and other information, such as perceived risk, rather than underlying concerns. Consequently, this may avoid mental imagery and anxiety associated with the consequences of recurrence, namely progression of their disease leading to death. If FCR represents cognitive avoidance of FOP, then it would be expected that only FCR is predicted by worry about present somatic sensations, and that risk perception would be more closely related to FCR, and the concerns underlying FOP may be more existential. This could also account for the correlation between FCR and FOP, and the

finding that both fears tend to be strongest in people with active disease (see supplementary materials).

### 3.1 | Clinical implications

These results have important clinical implications. The most comprehensive meta-analysis of psychological interventions for FCR included studies that used either FCR or FOP as an outcome, had only 3 studies that focused on FOP. The results of that meta-analysis

found that contemporary forms of cognitive behavioural therapy (CBT; e.g. acceptance commitment therapy, mindfulness) led to greater reductions in FCR than traditional CBT.<sup>17</sup> However, two of the three studies that assessed FOP were included in the traditional CBT group ( $k = 9$ ). In contrast, all of the contemporary CBT trials measured FCR. Therefore, it is possible that the smaller effects observed for CBT were due to the inclusion of trials for FOP.

The major difference between contemporary and traditional CBT is that traditional CBT includes strategies that attempt to challenge people's beliefs, such as the perceived risk of recurrence. Our results demonstrate that the perceived risk of recurrence is more strongly associated with FCR than FOP. Therefore, it is likely that challenging perceived risk of recurrence would be less effective for FOP than FCR. It is possible that the conflation of FOP and FCR may provide suboptimal recommendations for clinical practice by drawing conclusions about one construct which do not apply to the other. While this remains speculative, it is essential that future studies distinguish between FOP and FCR, since our research clearly shows that they are not the same construct, nor are they associated with the same psychological variables. Therefore, it would not be surprising if different psychological interventions were optimal for each. The development of such optimised interventions will be critical in addressing the significant impact of these fears on those impacted by cancer.

### 3.2 | Study limitations

Despite careful consideration of the methodology, the present study must be qualified by some limitations. Firstly, we only included two types of cancer that predominantly affect women: ovarian and breast cancer. Therefore, whether these results generalise to men or those impacted by other cancers is unclear. Secondly, we tested a simplified version of Fardell et al.'s cognitive processing model.<sup>13</sup> It is unclear whether other constructs that have been theorised to contribute to FCR and/or FOP are associated with either or both constructs (e.g. interpretation biases<sup>14</sup>; death anxiety).<sup>15</sup> Future research is needed to test these different constructs and their relevance to FCR and FOP. Lastly, the FCR-I instructs participants that items about cancer recurrence refer to 'the possibility that the cancer could return or progress'.<sup>5</sup> These instructions were maintained to ensure our findings were relevant to the existing literature. Consequently, our results may reflect the different aspects of FCR and FOP that are measured by the FCR-I severity subscale and FoP-Q-SF. Yet if this were the case, since both measures are the most popular measures of FCR and FOP, and are used interchangeably, our results would still demonstrate an important distinction between what these questionnaires measure.

### 3.3 | Conclusions

The present study is the first to demonstrate that fear of the cancer returning or progressing are not synonymous. This study shows that the conflation of FCR and FOP is not warranted. This novel

exploration of construct equivalence has demonstrated that whilst FCR and FOP are related, they are clearly distinct constructs, which contradicts the predominant understanding of FCR. The fact that FCR and FOP are different constructs is far from trivial. While some predictors common to FCR and FOP were identified, namely meta-cognitions, intrusions and, to a lesser extent, perceived risk of recurrence, other differences emerged. The propensity to monitor one's body for threat by checking and reassurance seeking was uniquely associated with FCR and not FOP. Moreover, bodily threat monitoring was a strong predictor of FCR. If theoretical models differ, it is likely that interventions based on those theories will also be differentially effective for FCR and FOP. Therefore, future research needs to separate these constructs, and more research specifically for FOP is needed to ensure that psycho-oncology services can provide optimally effective treatments for survivors with FCR and/or FOP.

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### CONFLICT OF INTEREST

The authors have no conflicts of interest to report.

### DATA AVAILABILITY STATEMENT

Individual, but deidentified participant data and a data dictionary will be made available from publication upon request to researchers who aim to use the data in secondary analyses.

### ORCID

Louise Sharpe  <https://orcid.org/0000-0002-8790-6272>

Daniel Costa  <https://orcid.org/0000-0002-6111-0620>

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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