



*Fear of cancer recurrence, anxiety and depression in partners of cancer survivors*

Louise O'Rourke<sup>a</sup>

Supervised by Dr Peter Fisher<sup>a</sup>, Dr Gemma Cherry<sup>a</sup> and Dr Sophie Campbell<sup>b</sup>

<sup>a</sup>*Institute of Population Health, University of Liverpool, UK*

<sup>b</sup>*Royal Liverpool and Broadgreen University Hospitals NHS Trust, Liverpool, UK*

Submitted in partial fulfilment of the Doctorate in Clinical Psychology,

University of Liverpool,

July 2020

## Acknowledgements

I would like to thank my research supervisors, Dr Peter Fisher, Dr Gemma Cherry and Dr Sophie Campbell for their feedback and help in guiding me through the research process.

Additionally, I would like to thank my family for their ongoing encouragement, understanding and support. I would also like to thank my friends, particularly the friends that I have made whilst on the DClin journey – I'm so glad we survived this process together! A special thank you to my partner, Fraser, who has been a constant support and never failing to make me smile even during the most difficult and stressful times! Thank you.

Finally, I would like to thank all of the charities and support groups that helped to advertise the project to partners of cancer survivors, and a special thanks to the participants who kindly gave their time to participate in this study, as without them this research would not have been possible.

Total thesis word count = 18,626

## Table of Contents

Thesis overview	<b>1</b>
References	<b>2</b>
Chapter One	<b>3</b>
Fear of cancer recurrence in family caregivers of cancer survivors: A systematic review	<b>3</b>
Abstract	<b>5</b>
1. Introduction	<b>6</b>
2. Method	<b>9</b>
2.1 Review conduct and reporting	9
2.2 Search strategy	9
2.3 Inclusion and exclusion criteria	9
2.4 Study selection	10
2.5 Data extraction	10
2.6 Risk of bias	11
3 Results	<b>11</b>
3.1 Study characteristics	12
3.2 Results of assessment of risk of bias	13
3.3 Fear of cancer recurrence	13
3.4 Demographic factors	14
3.5 Clinical factors	14
3.5.1 Time since diagnosis and treatment	14

3.5.2	Cancer stage and severity	15
3.6	Comorbidities	15
3.6.1	Treatment type	15
3.6.2	Medical follow-up	16
3.7	Psychosocial factors	16
3.7.1	Emotional distress	16
3.7.2	Interpersonal factors	17
3.7.3	Stress and coping	18
3.7.4	Quality of life	19
3.7.5	Psychological mechanisms	19
4	Discussion	<b>20</b>
4.1	Methodological limitations and implications for research	24
4.2	Clinical implications	25
4.3	Conclusions	26
5	References	<b>45</b>
	Chapter Two	<b>61</b>
	The role of metacognition in fear of cancer recurrence, anxiety and depression in partners of cancer survivors	<b>61</b>
	Abstract	<b>62</b>
1.	Background	<b>63</b>
2.	Method	<b>65</b>
2.1	Participants	65

2.2	Procedure	66
2.3	Measures	67
2.3.1	Dependent variables	67
2.3.2	Independent variables	67
2.4	Analysis	68
2.4.1	Power calculation	69
3	Results	<b>69</b>
3.1	Sample characteristics	69
3.2	Correlations	71
3.3	Metacognitive beliefs and FCR, anxiety and depression	72
4	Discussion	<b>74</b>
4.1	Demographic and clinical characteristics	74
4.2	Metacognitive beliefs and FCR, anxiety and depression	75
4.3	Study limitations	77
4.4	Clinical implications	77
4.5	Conclusion	78
5	References	<b>80</b>

## Tables and Figures

### Chapter one: Systematic Review

Figure 1. Flowchart of literature search	27
--	----

Table 1. Measures of demographic, clinical and psychosocial factors	28
---	----

Table 2. Study characteristics	29
Table 3. Assessment of risk of bias	33
Table 4: Main study findings	35
Chapter two: Empirical paper	
Table 1. Sample characteristics	70
Table 2. Descriptive statistics and Spearman's Rho correlations between the study independent variables and FCR, anxiety and depression	72
Table 3. Summary of the final models of hierarchical regression predicting FCR, anxiety and depression	74
Appendices	
Appendix A. Author guidelines for Psycho-Oncology journal	88
Appendix B. Data extraction form	90
Appendix C. Email correspondence from authors	91
Appendix D. Quality assessment form	92
Appendix E. Participant information sheet	94
Appendix F. Consent form	98
Appendix G. Ethics approval letter	99
Appendix H. Research advert	102
Appendix I. Debrief sheet	103
Appendix J. Fear of Recurrence Questionnaire	104
Appendix K. Hospital Anxiety and Depression scale	106
Appendix L. Demographic and clinical information	107
Appendix M. Metacognitions Questionnaire-30	108

Appendix N. Cognitive Attentional Scale-1	110
Appendix O. SPSS data output	112



## Thesis overview

Cancer survivorship is increasing worldwide as a result of improvements in treatment and earlier diagnosis and prevention (1). Yet not only do cancer survivors continue to experience adverse physical and psychological effects from the illness (2-4), those who are close to them, particularly their caregivers and partners, also report significant psychological difficulties. These include increased levels of anxiety, depression and worries that the cancer may return. Examining the psychological mechanisms underpinning anxiety, depression and fear of cancer recurrence (FCR) in partners of cancer survivors is critical to the development of psychological interventions for this population.

The first chapter in this thesis is a systematic review that aimed to narratively synthesise cross-sectional and longitudinal studies that have measured demographic, clinical and psychosocial correlates and predictors of FCR. This was selected as although two reviews have examined FCR in caregivers (2, 5), there has been no systematic synthesis of studies assessing correlates and predictors of caregivers' FCR.

The second chapter in this thesis is an empirical paper that investigated, for the first time, the utility of a transdiagnostic psychological model of emotional distress, the Self-Regulatory Executive Function (S-REF) model (6), for understanding emotional distress experienced by adult partners of adult cancer survivors. The aim of this study was to test whether metacognitive beliefs (beliefs about thoughts) were associated with FCR, anxiety and depression in partners of cancer survivors, whilst controlling for demographic and clinical variables.

Both the review and empirical paper were prepared for submission to *Psycho-Oncology* and have been formatted in line with the author guidelines (Appendix A). This journal was chosen as it focuses on the psychological aspects related to cancer and is concerned with the psychological responses of families and caregivers to cancer. The

findings from the review and empirical paper have potential clinical implications for future development of psychological interventions for caregivers of cancer survivors.

### References

1. Arnold M, Rutherford MJ, Bardot A, Ferlay J, Andersson TM, Myklebust TÅ, et al. Progress in cancer survival, mortality, and incidence in seven high-income countries 1995–2014 (ICBP SURVMARK-2): a population-based study. *Lancet Oncol.* 2019;20(11):1493-505.
2. Simard S, Thewes B, Humphris G, Dixon M, Hayden C, Mireskandari S, et al. Fear of cancer recurrence in adult cancer survivors: A systematic review of quantitative studies. *J Cancer Surviv.* 2013;7(3):300-22.
3. Pitceathly C, Maguire P. The psychological impact of cancer on patients' partners and other key relatives: a review. *Eur J Cancer.* 2003;39(11):1517-24.
4. Williams F, Jeanetta SC. Lived experiences of breast cancer survivors after diagnosis, treatment and beyond: qualitative study. *Health Expect.* 2016;19(3):631-42.
5. Maheu C, Galica J. The fear of cancer recurrence literature continues to move forward: a review article. *Curr Opin Support Palliat Care.* 2018;12(1):40-5.
6. Wells A, Matthews G. Attention and emotion: A clinical perspective: Psychology Press; 1994.

*Chapter One*

**Fear of cancer recurrence in family caregivers of cancer survivors: A systematic review**

Louise O'Rourke<sup>a</sup>

Supervised by Dr Peter Fisher<sup>a</sup>, Dr Gemma Cherry<sup>a</sup> and Dr Sophie Campbell<sup>b</sup>

<sup>a</sup>*Institute of Population Health, University of Liverpool, UK*

<sup>b</sup>*Royal Liverpool and Broadgreen University Hospitals NHS Trust, UK*

Word count = 9,287

### Abstract

**Objective:** Fear of cancer recurrence (FCR) is a significant concern for family caregivers of cancer survivors and is associated with various adverse outcomes, including increased emotional distress and poorer quality of life. Although several theoretical models have been proposed to account for FCR in cancer patients and survivors, their applicability to caregivers is unknown. The aim of this review was to identify clinical, demographic and psychological factors that are associated with, and predict, FCR in caregivers of cancer survivors. **Method:** AMED, CINAHL, Medline, PsycINFO and Scopus were systematically searched for relevant studies. Studies were included if they reported quantitative data on factors associated with FCR or similar constructs (e.g., worry or anxiety about cancer recurrence) in family caregivers of adult cancer survivors. Included studies were assessed for methodological quality using a standardised checklist. **Results:** Sixteen studies, half of which were cross-sectional, were included and summarised narratively. Non-modifiable factors, including age and treatment modality were consistently associated with increased FCR. Significant positive associations were also reported between illness perceptions and FCR. However, small numbers of studies reported on each of the demographic, clinical and psychological factors. There were also several methodological limitations to the included studies, as half of the studies were cross-sectional, and most reported data from the USA. **Conclusions:** Research examining FCR in caregivers of cancer survivors has predominantly focused on demographic and clinical factors. Given the paucity of research exploring the psychological mechanisms of FCR, future research should investigate theoretical underpinnings of FCR in caregivers of cancer survivors to support the development of psychological interventions for this population.

**Keywords:** Cancer survivors, family caregivers, fear, recurrence, systematic review

## 1. Introduction

The number of new cancer diagnoses in England is increasing each year, with incidence rates in the United Kingdom now ranked higher than two-thirds of Europe (1). Yet despite the increase in diagnosis, cancer survival rates in the United Kingdom have doubled in the last 40 years, with approximately half of people diagnosed with cancer in England and Wales now surviving for 10 years or more post-diagnosis (2, 3). Comparable results have been demonstrated world-wide (Australia, Canada, Denmark, Ireland, New Zealand, Norway), whereby 1-year and 5-year survival rates have increased across almost all cancer types (4). Although improvements in health care have led to earlier diagnosis and more effective, targeted medical treatment (4), family caregivers of survivors continue to experience adverse effects of the illness, both physically and psychologically (5-7). Specifically, cancer caregiving responsibilities can result in issues such as pain, fatigue, financial difficulties and social isolation (7, 8).

One of the most distressing concerns for survivors and their families is fear of cancer recurrence (FCR) (9), defined as “fear, worry, or concern about cancer returning or progressing” (10). Prevalence of FCR is estimated to range between 39 and 97% in cancer survivors (11), and is thought to remain stable over time, persisting even after completion of acute medical treatment (11-13). Prevalence rates of FCR are also high in family caregivers (14) and, in some cases, can be higher than for the patients themselves (15, 16). Managing worries about cancer returning is a commonly-reported unmet need for caregivers (17-19), which is associated with elevated emotional distress (16) and poorer quality of life (QoL) (11).

Various theoretical models have been proposed to account for the psychological mechanisms underpinning FCR in cancer patients and survivors. These include the Common Sense Model (CSM; 20), the Self-Regulatory Executive Function (SREF; 21) model and

Social-Cognitive Processing Theory (SCPT; 22). The CSM (20) suggests that internal and external cues activate cognitive responses associated with FCR. In contrast, The S-REF model (21) argues that the development and maintenance of emotional distress is driven by cognitive processes rather than the content of thoughts themselves, whereas the SCPT (22) proposes that the social environment can act to either encourage or deter cognitive processing of the cancer experience.

It is argued that many of the theoretical frameworks used to understand FCR in cancer survivors consist of similar components, including internal (e.g., physical symptoms, treatment side effects) and external (e.g., clinical follow-up) cues that trigger a cognitive response associated with FCR (23). Following an appraisal of such cues, a variety of coping responses, some less helpful than others, are implemented which are influenced by the social environment and other contextual factors (23, 24). Such coping responses may include avoidance, limited future planning, symptom checking and misinterpretation of symptoms, and reassurance seeking from health professionals and family members, which in the longer term can increase FCR (24).

More recently, a blended model of FCR (25) has been developed which incorporates the CSM and Uncertainty in Illness Theory (26). As FCR is deemed to share similarities with worry (9), the blended model also comprises of cognitive theories of worry (27-29). It argues that reduced tolerance for uncertainty and metacognitions (beliefs about thoughts) are key factors in the maintenance of worry. Findings from this model indicate that triggers, perceived risk of recurrence, and illness uncertainty predict survivor FCR, whilst positive beliefs about worrying and intolerance of uncertainty do not directly predict FCR but act indirectly by increasing maladaptive coping (25, 30).

Psychological interventions for FCR in patients have been predominantly based on cognitive behavioural approaches to address the behavioural and psychological responses of

unhelpful coping responses (23, 24). Yet, in line with the assumptions proposed by the blended model of FCR (25), interventions that focus on cognitive processing and metacognitions in FCR, such as worry, rumination or attentional bias, rather than the content of thoughts, have been found to be more effective in comparison to traditional cognitive behavioural approaches (31). Certain components from interventions including metacognitive therapy and acceptance and commitment therapy may be appropriate for targeting such processes (32).

Similar to cancer survivors, caregivers often engage in unhelpful coping responses such as avoidance of cancer-related discussions, reluctance to make plans for the future and reassurance seeking (30, 33). Furthermore, although caregivers do not experience internal cancer-related cues, it is argued that the cancer journey is experienced by the family as a whole (34). Therefore, caregivers are likely to be aware of survivors' physical experiences of cancer diagnosis and treatment, through helping patients to manage symptoms and treatment side effects (33). Furthermore, caregivers are exposed to an array of external cues and situations which may trigger FCR, including cancer-related conversations, media references to cancer, appointments with health professionals and survivors' follow-up appointments and feeling unwell themselves (35). Models of FCR in cancer survivors may therefore be applicable to understanding FCR in caregivers. However, it is currently unclear if similar components are relevant in relation understanding FCR experienced by caregivers of cancer survivors, or indeed, if there are other factors which are significant in the development of FCR in this population.

In order to develop more effective interventions for this group, we need to better understand the psychological processes underpinning FCR. Although two reviews have examined FCR in caregivers (11, 36), no systematic synthesis of studies examining correlates and predictors of caregivers' FCR exists. This systematic review aims to address this need by



critically appraising and synthesise the findings of quantitative studies investigating demographic, clinical and psychosocial correlates or predictors of FCR in family caregivers of adult cancer survivors. Areas for further research, clinical implications and areas of intervention will be outlined.

## **2. Method**

### **2.1 Review conduct and reporting**

Review conduct and reporting adheres to recommendations by the Centre for Reviews and Dissemination (37) and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidance (38). The protocol was registered on the international prospective register of systematic reviews, Prospero, in January 2019 (reg. number CRD42019119729) and can be accessed at <https://www.crd.york.ac.uk/PROSPERO>.

### **2.2 Search strategy**

AMED, CINAHL, Medline, PsycINFO and Scopus were systematically searched for published literature using the following search terms: partner (partner\*, couple\*, spous\*, dyad\*, carer, caregiver, care-giver, care giver, caregiv\*, husban\*, wife or wives) and (fear\* or worry\* or anxiety\* or cancer\* or afraid) and (recur\* or relaps\* or reoccur\* or return\* or progress\*) and (cancer\* or tumor\* or tumour\*). There were no restrictions placed on publication date. Searches were repeated in March 2020 to identify any new publications relevant to the review question.

### **2.3 Inclusion and exclusion criteria**

To be included in the review, studies had to report quantitative data on factors associated with FCR or similar constructs (e.g., worry or anxiety about cancer recurrence) in adult family caregivers (partners, family members and close friends) of adult cancer survivors (both aged  $\geq 18$  years). Patients were classed as cancer survivors if they had received a

diagnosis of cancer at least 6 months ago, had completed acute medical treatment for cancer and had not been diagnosed with a secondary cancer. Articles had to be published in English in a peer-reviewed journal. Studies were excluded if cancer patients had not yet received treatment, in order to ensure findings were deemed to be taken from a survivorship phase. Studies which did not report data separately for cancer survivors were also excluded (e.g. studies reporting data from survivors and patients with metastatic disease). All case studies, commentaries, conference abstracts, dissertations, editorials, qualitative studies and review articles were excluded.

#### **2.4 Study selection**

Two reviewers (LOR and AW) independently assessed the titles and abstracts of potentially relevant papers. The reviewers then independently reviewed the full-text papers against the inclusion and exclusion criteria. Papers which did not meet the inclusion criteria were removed. Discrepancies were discussed with the wider research team (MGC, PF, SC) until a negotiated conclusion was reached.

#### **2.5 Data extraction**

For each study, relevant demographic, methodological and summary data were extracted using a standardised data extraction form (Appendix B) by LOR and independently checked for accuracy by AW. Disagreement or uncertainty was resolved through discussion with the wider research team. Authors were contacted if data were unclear or had not been reported within the paper (Appendix C). The following information was extracted: (i) author, (ii) year of publication, (iii) study design, (iv) clinical and treatment characteristics of the survivor (diagnosis, stage, time since diagnosis and treatment type), (v) caregiver demographics, (age, gender, ethnicity and relationship length), (vi) main findings, including

correlates and predictors of FCR. Where studies reported multiple analyses, only data from the most complex relevant multivariate analyses were extracted. Studies that reported data from the same larger database, but focused analyses on different outcomes were interpreted and referred to as separate studies, with their linked status noted.

## 2.6 Risk of bias

Studies were assessed for risk of bias using a quality appraisal tool adapted from the Agency for Healthcare Research and Quality (Appendix D) (39), which assesses risk of bias in studies across various domains relevant to research with physical health populations. This tool was considered appropriate to use in this review as it considers risk of bias across key methodological areas, such as sample selection, size, description, handling of missing data and analysis (40), thus allowing for comparison of studies across domains. Two reviewers (LOR and AW) separately assessed risk of bias in the included studies. Uncertainty was resolved through discussion with the wider research team (MGC, PF, SC). In line with Centre for Reviews and Dissemination (37) guidance, studies were not excluded based on outcome of the risk of bias assessment.

## 3 Results

The search strategy identified 1729 potentially relevant records. After exclusion of duplicates and screening of titles and abstracts, 40 potentially eligible articles remained. After reviewing their full-text, 8 articles, reporting 7 studies, were identified for inclusion for review. Nine studies were identified during the updated search, resulting in the inclusion of 19 articles, reporting 16 studies\*. The process of identification of papers to inclusion for

---

\* The samples of Janz et al. (41), Soriano et al. (42), Soriano et al. (43), Soriano et al. (44) and Perndorfer et al. (45) were drawn from a larger database (SEER). Soriano et al. (43) and Soriano et al. (44) used the same sample and therefore will be considered as one study. Janz et al. (41), Soriano et al. (42) and Perndorfer et al. (45) studied

review is summarised in Figure 1. Various areas, including demographic, clinical and psychosocial factors, were examined in the studies and are summarised in Table 1.

### 3.1 Study characteristics

The main characteristics of the studies are displayed in Table 2. Nine studies, reported in 12 articles, were conducted in the USA (41-45, 48-54). The remainder were conducted in Taiwan (55), UK (46, 47, 56), Ireland (57), The Netherlands (58) and China (59). Studies used a convenience or purposive sampling strategy and were either cross-sectional (41, 42, 46, 48-53, 57, 58) or longitudinal surveys (42-45, 47, 54-56, 59). Seven studies recruited patients with breast cancer, four with head and neck cancer, three with prostate cancer, and two with mixed cancer diagnoses. The shortest time since diagnosis or treatment was 90 days (54), whilst the longest time was 7.3 years (*SD* 3.6) (49).

Out of the 16 studies, nine focused on partners (41-45, 50, 54, 55, 58, 59), whilst seven studies reported data on caregivers, including other family members and friends. Caregivers were predominantly White, female and middle-aged. Education level varied across studies, with college or above tending to be the most commonly reported education level. Relationship length varied, with the longest mean length of relationship between caregiver and survivor being 43.0 years (range 8-57 years) (58) and the shortest being 24.40 years (*SD* 13.8) (42).

Eight studies, reported in nine articles, compared the mean FCR scores of survivors and caregivers. Of these, five studies, reported in 6 articles found that carers had significantly

---

non-overlapping samples, thus will be interpreted and referred to as separate studies. Similarly, samples of Dempster et al. (46) and Graham et al. (47) were drawn from a larger study (OPA, UK) but will be interpreted as separate studies as they used non-overlapping samples. Mellon and Northouse (48) Mellon et al., (2006, 2007, 2001) were based on data from the MDCSS database and used the same sample, therefore will be considered as one study.

greater levels of FCR than survivors (41, 52-54, 56, 58); whilst one study found that patients reported significantly higher FCR than spouses (44).

### **3.2 Results of assessment of risk of bias**

The risk of bias assessment results are outlined in Table 3, which indicate that the majority of areas, including unbiased selection of cohort, validated measures of outcome and dependent variables, and appropriate analyses rated highly. Several limitations were identified in relation to study design, assessment of FCR and justification of sample sizes. Only five studies reported a sample size calculation (51, 52, 56-58). Out of the 16 studies, only nine studies were found to report an adequate follow-up period. However, half of the studies included for review were cross-sectional therefore could not be assessed against the adequate follow-up criteria. Most studies provided adequate descriptions of the study cohort, but three studies underreported demographic data (46, 47, 59). Most used validated methods for assessing predictor variables; however, in one study (43), it was not clear if the measures used had been validated. Most studies used validated measures of assessing FCR; however, in four studies (41, 51, 54, 59), it was unclear if adapted measures had been validated. In one study, it was not clear if confounding demographic variables had been controlled for in analyses (55).

### **3.3 Fear of cancer recurrence**

Most studies found that caregivers experienced moderate levels of FCR, however, three studies, reported in four articles, reported very low levels of FCR (42-45). One study found that 49% of partners had high levels of FCR and 57% of highly fearful partners were in a relationship with a highly fearful survivor (58). Furthermore, prospective studies reported that caregiver FCR remained stable over time, ranging from six months to three years post-

treatment (47, 54, 56). Of these, one study used an adapted measure of FCR (54), thus it is unclear if this is a validated instrument. The remainder used validated measures of FCR (47, 56).

### **3.4 Demographic factors**

Data indicated support for significant associations between age and FCR. Twelve studies, reported in 13 articles, examined the relationship between age and FCR. Of these, one study found a weak negative association between age and FCR ( $r = -.17$ ) (51) whilst five studies reported a significant association which remained significant when other clinical and demographic variables were controlled for (42, 46, 53, 57, 58). However, there were no details regarding cancer stage and treatment type in one of these studies (46). Four studies assessed the relationship between gender and FCR, one of which found a significant weak association between gender and FCR, with female carers reporting higher FCR than male carers (57). Of the three studies that assessed the relationship between ethnicity and FCR, only one found a significant relationship, reporting that Latino partners were significantly more likely to worry than White partners, whilst Black partners were less likely to report worry (41). However, as this study used an adapted FCR measure, it is not clear if this has been validated. Seven studies assessed the relationship between education and FCR. Of these, one study found a very weak negative association between education and FCR ( $r = -.16$ ) (50), however as there is no evidence of a sample size calculation, it is unclear if the study is sufficiently powered.

### **3.5 Clinical factors**

#### **3.5.1 Time since diagnosis and treatment**

There was limited support for significant associations between time since diagnosis and FCR. Two out of the eight studies that assessed the relationship between time since

diagnosis and FCR found that those caring for more recently diagnosed survivors reported higher FCR (49, 57) which remained significant when controlling for other demographic and clinical factors (57). Of these studies, one study met all of the quality assessment criteria (57), however sample size calculation was not reported in Boehmer et al. (49)'s study, which may indicate issues regarding statistical power and potential for Type I errors.

### **3.5.2 Cancer stage and severity**

Seven studies explored the relationship between cancer stage and FCR, none of which found a significant association (41, 49, 51, 53, 55-57). One study assessed the relationship between cancer severity and FCR, and found a significant positive association when controlling for other demographic and clinical variables (51). However, as this study used an adapted FCR measure, it is unclear if this has been validated.

## **3.6 Comorbidities**

Limited support was found for significant associations between comorbidities and FCR. Of the five studies that assessed the relationship between comorbidities and FCR, two found that greater number of comorbidities resulted in higher FCR when controlling for other variables, specifically survivor comorbidities (49) and caregivers' own reported number of comorbidities (41). One study examined the relationship between FCR and survivor's physical health and found that increased caregiver FCR was associated with poorer physical health of survivors (51).

### **3.6.1 Treatment type**

Data demonstrated mixed support for significant associations between treatment modality and FCR. Seven studies assessed the relationship between type of treatment and FCR. Of these, one study reported a very weak positive association between chemotherapy

and FCR ( $r = .14$ ) (57), whilst three studies reported significant results which remained significant after controlling for other demographic and clinical variables (41, 49, 54, 57). Those caring for survivors who had received anti-oestrogen therapy (49) or chemotherapy (41, 57) reported higher FCR. Two studies found that those caring for survivors who had undergone major surgery were more likely to have lower FCR (54, 57). This finding was significant when controlling for other demographic and clinical variables at 6 months post-treatment, but not at the 12 month time point (54).

### **3.6.2 Medical follow-up**

One study, reported in two articles, used a three week diary to investigate the impact of a mammogram on FCR, which reported that there was a significant increase in FCR during days leading up to the mammogram, and avoidance of threatening stimuli was predictive of FCR on the day of the mammogram (44). However, it was not stated whether confounding demographic variables were controlled for in this analysis. Following the mammogram, partner responsiveness (response perceived as genuine and enthusiastic) predicted lower caregiver FCR, whilst patient capitalization attempts (disclosure of positive events) predicted greater FCR at week 3 (43). However, Soriano et al. (43) did not report sample size calculation, therefore findings may be at risk of Type I errors.

## **3.7 Psychosocial factors**

### **3.7.1 Emotional distress**

There were significant associations found between level of anxiety and FCR. Three studies assessed the relationship between anxiety and FCR, all of which reported a weak positive association between anxiety and higher FCR ( $r = .24$  to  $.39$ ) (42, 44, 51). One study examined the relationship between emotional distress (anxiety and depression combined) and



FCR, and reported a strong positive association ( $r = .73$ ) (56). One study examined the relationship between negative affect and FCR, which found that as spousal negative affect increased, so did FCR level (42).

### 3.7.2 Interpersonal factors

Data indicated mixed support for significant associations between survivors and family caregivers (Table 4). Nine studies, reported in ten articles, assessed the relationship between survivors and caregiver FCR. Of these, eight studies found weak to moderate associations between survivor and family caregiver FCR scores ( $r = .19$  to  $.53$ ) (42, 44, 45, 48, 49, 51, 53, 58), which remained significant when controlling for other variables at 6 months post-diagnosis (56). However, the quality of studies that report these findings are mixed, as six of the nine studies do not report a sample size calculation (42, 44, 45, 48, 49, 53), whereas three studies did state this calculation (51, 56, 58). Consequently, it is unclear if the aforementioned studies are sufficiently powered and are potentially at risk of Type I errors.

Two studies examined the association between relationship quality and FCR, with one study reporting a significant positive association which was also found in next-day FCR when measured over 21 days (42). Three studies, reported in five articles, assessed the relationship between social support and FCR. Of these, one study found that social support was significantly negatively associated with FCR when controlling for other variables (49). One study investigated the relationship between loneliness and FCR, reporting a weak positive association between loneliness and FCR ( $r = .27$ ) (57).

Five studies investigated the impact of communication on FCR, all of which found significant results. Specifically, on a day that partners perceived the cancer survivor to be less available or responsive to discussions of cancer-related worries, partners were more likely to have greater FCR on that same day, but not the next day (42). One study found that patient

disclosures of positive events resulted in decreased FCR as did partner responsiveness which was perceived to be genuine and enthusiastic (43). However, it is unclear if the adapted measure used to assess partner responsiveness is validated. Similar findings were reported whereby partners' perceptions of positive information (e.g., supportive and inclusive) and negative information (e.g., indifferent) resulted in a change in FCR (59). One study reported that cognitive processing mediated the relationship between social constraints and FCR (50). Attempting to protect one's partner by hiding cancer-related concerns was weakly positively associated with increased FCR ( $r = .15$ ) (45).

### 3.7.3 Stress and coping

Two studies, reported in four articles, assessed the relationship between stressors and FCR, all of which found significant results. Specifically, care-related stressors (financial impact and time-burden associated with caregiving) (57) were positively associated with FCR, whilst a weak positive relationship was reported between stressors related to ill health and FCR ( $r = .24$  to  $.29$ ) (48, 52, 53).

Two studies assessed the relationship between coping strategies and FCR. Of these, one study reported a weak positive association between interpersonal coping (e.g., seeking support from cancer survivor) and FCR ( $r = .35$ ) (46), whilst another study found that this association remained significant when other variables were controlled for (47). Although the latter study indicated a 40% drop out rate over time, there were no significant differences on depression or FCR between participants who provided complete data and those who provided data at one time point only (47). One study found that increased use of reflection and relaxation was a significant predictor of higher FCR at 12 months follow-up, whilst those with a hopeful and in-control outlook exhibited lower FCR (47). The authors suggest that the association between increased use of diversionary and relaxation coping skills and greater

anxiety may be indicative of such strategies reinforcing an aspect of avoidance, which may be beneficial in the short term but in the longer term, act to maintain anxiety.

### **3.7.4 Quality of life**

Four studies, reported in five articles, assessed the relationship between QoL and FCR. All studies found a significant result, indicating a weak positive association between QoL and FCR ( $r = -.28$  to  $.33$ ) (48, 51, 52, 57). Specifically, higher FCR was linked to lower QoL scores, including poorer caregiver mental health (51), lower survivor QoL (57) and poorer family QoL (48, 52). One study found significant differences between health-related QoL in partners with high and low FCR, reporting that partners with high FCR obtained significantly lower scores on social functioning, emotional role functioning, mental health, vitality and general health (58). The majority of the studies that reported on QoL met the key criteria of the quality assessment and reported on relatively large sample sizes ranging from 123 – 455.

### **3.7.5 Psychological mechanisms**

One study, reported in three articles, examined the relationship between the meaning of illness and FCR, reporting a weak negative association between negative meaning of illness and FCR ( $r = -.27$  to  $-.28$ ) (48, 52, 53). Three studies assessed the relationship between illness perceptions and FCR, all of which reported significant findings (46, 47, 59). Specifically, one study found that an understanding of the disease was negatively associated with FCR, whilst belief of less serious consequences and control over condition were positively associated with FCR (46). One study reported that caregivers with a reduction in beliefs of severe consequences and causes of the condition, and an increase in control beliefs and understanding of the condition was associated with decreased FCR over a 12-month time period (47). One study found that over a 10 day period, spouses' negative illness

representations were negatively associated with their own disclosures of positive information (59). However, this study did not state a sample size calculation therefore statistical analysis may be underpowered and at risk of Type I error rates.

#### 4 Discussion

This review summarised cross-sectional and prospective research investigating the demographics, clinical and psychological factors associated with FCR in caregivers of cancer survivors. Sixteen studies, reported in 19 articles, were included and summarised narratively. Non-modifiable factors, including age and treatment modality were consistently associated with increased FCR. Although there was only limited research investigating psychological mechanisms ( $n = 3$ ), significant associations were found between illness perceptions and FCR. Specifically, a good understanding of the cancer diagnosis was negatively associated with FCR, whilst belief of less serious consequences and control over the condition were positively associated with FCR.

Caregivers reported moderate levels of FCR which appeared to remain stable over time (47, 54, 56). This is in line with the cancer survivorship literature, whereby review findings suggest that FCR can be experienced for five or more years after the initial diagnosis (13). Notably, findings indicated that caregivers reported significantly greater levels of FCR than survivors (41, 52-54, 56). Caregivers have commonly been found to experience greater psychological distress compared to patients (60-62). Therefore, it would appear that family caregivers would benefit from further intervention and support, given the prevalence of psychological difficulties highlighted in the literature. Additionally, a significant association was found between caregiver and survivor FCR (48, 51, 53, 56, 58). An interdependent relationship has also been found to exist between patients' and caregivers' emotional distress

(63, 64), and research has suggested that interventions aimed at reducing distress should be delivered jointly, as treating patients and caregivers together might be effective than treating the patient alone (65). Therefore, it would appear that there is an argument for delivering joint interventions to treat FCR.

There were mixed findings with regards to demographic factors and level of FCR. Younger age was significantly associated with FCR (41, 42, 46, 51, 53, 57, 58), which has been commonly reported in the cancer survivorship literature and may be due to the unexpectedness of cancer in younger age and the perceived negative physical, social or economic impact of such a disease (66, 67). Limited significant outcomes were reported with regards to the remaining demographic factors. Similar findings have been reported in the cancer survivor literature, whereby no demographic, clinical or social factors reliably predicted subsequent distress in cancer survivors (68).

Of the 13 studies that assessed the association between clinical outcomes and FCR, six reported significant associations between clinical outcomes and FCR. Time since diagnosis (49, 57) was significantly associated with higher FCR, which contrasts with the cancer survivorship literature (11, 13, 69). Four studies found that treatment modality was significantly associated with FCR, which is consistent with the cancer patient and survivorship literature that indicates that different treatment approaches are significantly associated with FCR (70-72). Patients who have had chemotherapy or radiotherapy are likely to experience side effects, and an increased number of hospital trips and inpatient episodes, which may contribute to psychological morbidity (73). Furthermore, research has indicated that some patients may choose more invasive surgeries even when the risk of recurrence is low, in order to eliminate risk to the greatest possible extent (74). Consequently, caregivers may perceive surgery as a more conclusive treatment, and therefore may be of the view that

the cancer is less likely to return, as opposed to treatment side effects and multiple hospital trips which may act as triggers of FCR.

Only one study explored the association between clinical follow-up (mammogram) and FCR, which reported a significant association (44). This is consistent with research that suggests medical examinations and annual check-ups are triggers of FCR for cancer survivors (75, 76). It may be that cancer survivors who continue to have routine medical follow-up appointments report higher FCR, yet research also argues that survivors with high FCR schedule more frequent appointments to be feel more reassured (77). As caregivers often attend medical appointments with the survivor (33), it is likely that such follow-ups may also act as a trigger for FCR in caregivers. However, as only one study looked at clinical follow-up, conclusions cannot be drawn.

Two studies reported a significant association between comorbidities and caregiver FCR (41, 49). Similar findings have been reported in the cancer survivorship literature, with comorbidities found to be strongly associated with FCR (75, 78, 79). Internal physiological cues related to comorbid conditions may be misinterpreted as possible cancer recurrence, thus symptoms may act as a reminder of vulnerability and trigger FCR (20, 24, 69). For caregivers, they are likely to witness survivors expressing somatic concerns and reporting treatment side effects, therefore, caregivers may be more vigilant regarding changes in the survivors' physical health which may exacerbate worries that the cancer might return. Furthermore, lack of communication between the dyad may lead to worry regarding somatic concerns and side effects (42, 50). Again, similarly to demographic factors, it would seem that clinical indicators are not as critical as psychological factors in the development and maintenance of FCR, and there are intrapersonal factors which need to be considered.

There was a paucity of studies in the review that assessed psychological factors. Out of the psychosocial factors examined, communication appeared to have a significant impact

on FCR. The less someone was able to tell their partner about their cancer-related concerns, the more likely they were to experience FCR (42, 50). Research suggests that unsupportive partner behaviours (i.e., critical or avoidant responses) are associated with both patient and partner reports of hiding concerns and disengagement (80). One study reported that caregivers hiding their own cancer-related worries in an attempt to protect the survivor was associated with increased FCR (45), although this was a weak association and the study sample size was small. Similar findings have been highlighted in previous research, particularly caregivers' reluctance to discuss emotions relating to cancer for fear of burdening or upsetting the patient (33, 81). Consequently, it would appear that communication between the caregiver and survivor is an important area for further research.

The review findings indicated that caregivers relied on various coping strategies, including reflection, relaxation, diversion and interpersonal approaches (e.g., through requiring frequent reassurance regarding FCR), which were significant predictors of higher FCR (46, 47). Reassurance seeking and avoidance are common behavioural manifestations of FCR in cancer survivors (24, 25, 82). Research also highlights that caregivers engage in a high use of avoidance, distraction and denial (30, 83), yet acknowledge that such strategies are only temporarily effective (33). Consequently, it is likely that FCR is exacerbated and maintained as the psychological distress is not explicitly addressed.

Significant outcomes were reported for psychological mechanisms, specifically illness perceptions (46, 47, 59). Similar findings have been reported in the cancer survivorship, as illness perceptions have been associated with higher FCR and worry about cancer more generally (11, 82, 84). Furthermore, individual interpretations or representations are often more influential than clinical characteristics in determining FCR (66). However, a review of psychological distress in cancer survivors reported no consistent evidence that measures of illness appraisal predicted longer-term distress (68). Although only a small proportion of the

studies included in the review examined psychological mechanisms, the findings provide a strong argument for further research to be carried out in this area in order to enhance understanding.

#### **4.1 Methodological limitations and implications for research**

The review identified significant findings with regards to associations and predictors of FCR in caregivers of cancer survivors. However, there are several limitations which must be taken into consideration. As only published data were searched and included in this review, there is a possibility that relevant studies were missed. Furthermore, only citations written in English were considered for inclusion for review, which may have resulted in a language, selection or cultural bias.

It is also important to consider the methodological limitations of the included studies. There is likely to be a risk of self-selection bias as recruitment methods were reliant on patients responding to the research adverts. Eight out of the 16 studies used a cross-sectional study design, thus precluding the ability to draw causal inferences. However, the nine prospective studies included in the review all reported an adequate follow-up period. Most studies reported data from the USA and participants were predominantly Caucasian females, thus may not reflect a representative sample of the population. It is also important to note that cancer patients were in different stages of diagnosis, therefore associations with FCR could differ as those caring for patients with more advanced cancer may perceive the diagnosis as being more serious and more likely to recur (11). Future research should attempt to address the observed limitations by recruiting larger, more representative samples of carers of patients with a range of different cancers.

With regards to the quality of studies, only five studies reported a sample size calculation, thus studies are potentially statistically underpowered and at risk of Type I error



rates. Researchers should ensure that this is stipulated in future research papers, in order to ensure confidence in the statistical power of findings. Only three articles considered the psychological mechanisms associated with FCR in family caregivers (46, 47, 59), whilst the remaining studies investigated demographic factors and interpersonal processes. Future research should consider the psychological processes that underpin FCR in caregivers in order to enhance current psychological interventions and support.

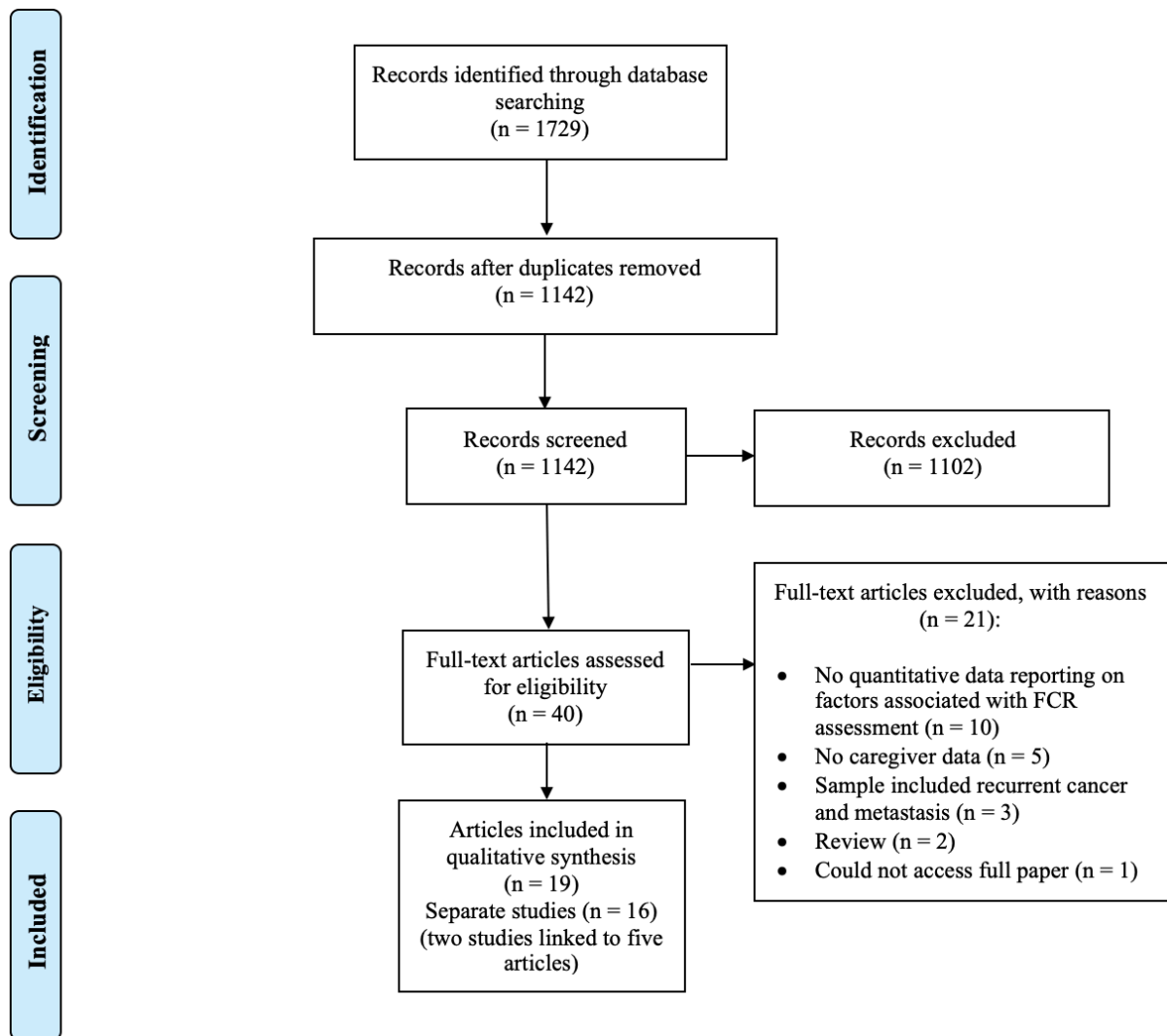
#### **4.2 Clinical implications**

A total of 16 studies examined the associations between demographic, clinical and psychological factors and caregiver FCR, yet as the studies looked at different aspects, it is therefore hard to draw conclusions from the review findings. Nonetheless, significant associations were found between FCR and certain demographic and clinical factors, including younger age and treatment modality. Health professionals may want to consider this when offering information on treatment approaches and providing the space to discuss concerns about recurrence. Previous research has identified a need for planning for transition from patient to ‘survivor’ (85, 86), which involves discussions around treatment, ongoing management, managing FCR and identifying triggers for seeking help and support from healthcare team (87). Caregivers should be included in care planning, where possible, in order to have the opportunity to raise any concerns about the cancer returning and have a clear sense of treatment approaches and ongoing support. In cases where the patient does not want the caregiver to be involved in the care plan, caregivers should be offered their own support as the cancer experience can result in the caregiver adapting to a “new normal” and potentially altered future and sense of self (81).

Given the paucity of research investigating psychological mechanisms underpinning FCR in caregivers of cancer survivors, further research which assesses psychological factors that are predictive of FCR is warranted before suggestions for interventions can be made.

### **4.3 Conclusions**

The results of the review indicate that caregiver FCR is a significant concern and highlights the importance of furthering current understanding of this prevalent issue. Weak to moderate associations were found between certain demographic and clinical factors and increased FCR. The limited research investigating the psychological mechanisms reported that illness perceptions explained additional variance in FCR when controlling for demographic and clinical characteristics. Further research examining modifiable factors are required, in order to enhance understanding of the psychological mechanisms that are involved in the development and maintenance of FCR in caregivers of cancer survivors. By investigating modifiable factors, this will provide evidence and guide the development of appropriate and effective interventions for this population.



**Figure 1.** Flowchart of literature search (based on PRISMA guidelines) (38)

**Table 1: Measures of demographic, clinical and psychosocial factors**

<b>Correlate or predictor variables</b>	<b>Studies analysing correlate or predictor variables</b>	<b>Studies with significant results (n)</b>
<i>Demographic (n = 12 studies reported in 13 articles)</i>		
Age	sig. (42, 46, 51, 53, 57, 58) n.s. (41, 47, 48, 49, 50, 55, 56)	6
Gender	sig. (57) n.s. (47, 53, 56)	1
Ethnicity	sig. (41) n.s. (50, 53)	1
Education	sig. (50) n.s. (41, 49, 53, 55, 56, 58)	1
<i>Clinical (n = 14)</i>		
Time since diagnosis	sig. (49, 57) n.s. (46, 47, 50, 51, 53, 58)	2
Cancer stage	n.s. (41, 49, 51, 53, 55-57)	0
Cancer severity	sig. (51)	1
Comorbidities	sig. (41, 49) n.s. (46, 47, 53)	2
Survivor physical health	sig. (51)	1
Treatment type	sig. (41, 49, 54, 57) n.s. (53, 55, 58)	4
Medical follow-up	sig. (43, 44)	2
<i>Psychosocial (n = 15 studies reported in 18 articles)</i>		
Anxiety	sig. (42, 44, 51)	3
Emotional distress	sig. (56)	1
Negative affect	sig. (42)	1
Survivor/caregiver FCR	sig. (42, 44, 45, 48, 49, 51, 53, 56, 58) n.s. (54, 55)	8 studies reported in 9 articles
Relationship quality	sig. (42) n.s. (55)	1
Social support	sig. (49) n.s. (48, 52, 53, 57)	1
Loneliness	sig. (57)	1
Communication	sig. (42, 43, 45, 50, 59)	4 studies reported in 5 articles
Stress	sig. (48, 52, 53, 57)	2 studies reported in 4 articles
Coping strategies	sig. (46, 47)	2
Quality of life	sig. (48, 51, 52, 57, 58)	4 studies reported in 5 articles
Meaning of illness	sig. (48, 52, 53)	1 study reported in 3 articles
Illness perceptions	sig. (46, 47, 59)	3

*Note.* sig = significant results; n.s. = Non-significant results;

**Table 2: Study characteristics**

Author, (year), country	Design	n	Age (years) (SD)	Caregiver		Cancer type	Survivor		
				Gender, n (%)	Relationship to survivor, n (%)		Stage, n (%)	Time since diagnosis (SD)	Treatment, n (%)
Boehmer et al. (2016), USA	Cross-sectional	H* 43	<i>M</i> = 62.4 (8.0)	Female: 7 (16.3) Male: 36 (83.7)	Partner: 36 (83.7) Child: 3 (7.0) Sibling: 2 (4.7) Parent: 1 (2.3) Friend: 1 (2.3)	Breast	I: 18 (42.9) II: 12 (28.6) III: 4 (9.5)	5.8 years (3.9)	L: 41 (95.3) M: 0 (0.0) M + (Re): 2 (4.7) R: 32 (74.4) H: 31 (72.1)
		M† 124	<i>M</i> = 55.8 (9.3)	Female: 116 (93.5) Male: 8 (6.5)	Partner: 106 (85.5) Child: 0 (0.0) Sibling: 3 (2.4) Parent: 3 (2.4) Friend: 12 (9.7)	Breast	I: 46 (37.1) II: 40 (32.3) III: 12 (9.7)	7.3 years (3.6)	L: 105 (84.7) M: 10 (8.1) M + (Re): 9 (7.3) R: 80 (64.5) H: 88 (71.0)
Chien et al. (2018), Taiwan	Longitudinal (T4 = 24 weeks)	T4 = 46	<i>M</i> = 62.0 (7.8)	Female: 48 (100.0) Male: 0 (0.0)	Partner: 48 (100.0)	Prostate	II: 30 (62.5) III: 18 (37.5)	Recruited when first diagnosed	S: 37 (77.1) R: 11 (22.9)
Cohee et al. (2017), USA	Cross-sectional	222	<i>M</i> = 47.98 (7.2)	Not reported	Partner: 222 (100.0)	Breast	Not reported	5.83 years (1.51)	Not reported
Dempster et al. (2011), UK	Cross-sectional	382	<i>M</i> = 62 (10.91)	Female: 257 (67) Male: 125 (33)	Partner: 359 (94.0) Other family: 23 (6.0)	Oesophageal	Not reported	<i>Mdn</i> = 46 months (19–81)	Not reported

\* Cancer survivors who identify as heterosexual women (HSW)

† Cancer survivors who identify as sexual minority women (SMW)

Author, (year), country	Design	n	Caregiver			Cancer type	Survivor		
			Age (years) (SD)	Gender, n (%)	Relationship to survivor, n (%)		Stage, n (%)	Time since diagnosis (SD)	Treatment, n (%)
Graham et al. (2016), UK	Longitudinal (T2 = 12 months)	171	<i>M</i> = 62.56 (10.05)	Female: 124 (72.5) Male: 47 (27.5)	Partner: 165(96.49) Other: 6 (3.51)	Oesophageal	Not reported	<i>M</i> = 4 years (2–7)	Not reported
Hodges & Humphris (2009), UK	Longitudinal (T2 = 6 months)	101	<i>M</i> = 56.26 (30 – 76)	Female: 73 (72.3) Male: 28 (27.7)	Partner: 86 (85.1) Non-partner: 15 (14.9)	Head and neck	1-2 = 27 (60) 3-4 = 16 (35.6) 5 = 2 (4.4)	Not reported	Not reported
Janz et al. (2016), USA	Longitudinal*	510	<50 N = 70 (13.7%) 50-65 N = 218 (42.75%) >65 N = 222 (43.5%)	Not reported	Partner: 510 (100.0)	Breast	0 :125 (24.5) I-II: 388 (66.3) III: 46 (9.0)	4 years	L: 324 (63.6) (U)M:128 (25.1) (B) M:51 (10.0) R: 363 (71.1) C: 229 (44.9)
Kim et al. (2012), USA	Cross-sectional	455	<i>M</i> = 56.19 (13.01)	Female: 288 (63.3) Male: 167 (36.7)	Spouse: 305 (67.1) Offspring: 84 (18.5) Other: 66 (14.4)	Mixed†	Localized: 292(64.2) Regional: 124(27.3) Distant: 39 (8.6)	2.2 years (0.40)	Not reported

\* Partners surveyed at Time 2 only

† Mixed cohort = breast, prostate, colorectal, lung, ovarian, kidney, uterine, bladder, non-Hodgkin's lymphoma, skin melanoma

Author, (year), country	Design	n	Caregiver			Cancer type	Survivor		
			Age (years) (SD)	Gender, n (%)	Relationship to survivor, n (%)		Stage, n (%)	Time since diagnosis (SD)	Treatment, n (%)
Maguire et al. (2017), Ireland	Cross-sectional	180	<i>M</i> = 57.3 (12.48)	Female: 136 (76.0) Male: 44 (24.0)	Spouse: 132 (73.4) Offspring or parent: 34 (18.8) Other: 14 (7.8)	Head and neck	I-II: 81 (54.4) III-IV: 68 (45.6)	4.9 years (3.79)	S: 31 (17.2) C: 47 (26.1) R: 122 (67.4)
Mellon & Northouse (2001); Mellon et al. (2006; 2007), USA	Cross-sectional	123	<i>M</i> = 55 (14.5) (21-80)	Female: 80 (65) Male: 43 (35)	Spouse: 65 (52.8) Child: 36 (29.3) Sibling: 10 (8.1) Significant other: 12 (9.8)	Mixed*	Not reported	3.39 years (1.0)	S: 108 (87.8) R: 48 (39.0) C: 28 (22.8) H: 4 (3)
Perndorfer et al. (2019), USA	Longitudinal (21-day diary)	69	<i>M</i> = 58 (10)	Not reported	Partner: 69 (100.0)	Breast	0: 8 (12) IA: 37 (53) IIA: 17 (25) IIB: 6 (9) IIIA: 1 (1)	5 months (2.09) after treatment	C: 21 (30) R: 50 (72) H: 58 (84)
Soriano et al. (2018a), USA Study (1)	Cross-sectional	46	<i>M</i> = 54.57 (13.31)	Not reported	Partner: 46 (100.0)	Breast	0: 11 (24) I: 17 (37) II: 15 (32) IIIA: 3 (7)	7.70 months after treatment	C and/or H: 15 (33)
Soriano et al. (2018a), USA Study (2)	Longitudinal (21-day diary)	72	<i>M</i> = 59.49 (10.34)	Male: 70 (97) Female: 2 (3)	Partner: 72 (100.0)	Breast	0: 10 (14) I: 34 (47) II: 27 (37) IIIA: 17 (23)	5.77 weeks after treatment	C: 24 (33) H: 58 (81)

\* Mixed cohort = Breast, prostate, colon-rectal, uterine

Author, (year), country	Design	n	Caregiver			Cancer type	Survivor		
			Age (years) (SD)	Gender, n (%)	Relationship to survivor, n (%)		Stage, n (%)	Time since diagnosis (SD)	Treatment, n (%)
Soriano et al. (2018b; 2019), USA	Longitudinal (21-day diary)	57	<i>M</i> = 60 (10)	Male: 55 (96) Female: 2 (4)	Partner: 57 (100.0)	Breast	0: 7 (12) IA: 30 (53) IIA: 14 (25) IIB: 5 (9) IIIA: 1 (1)	12.2 months (1.9)	C:17 (30) R: 41 (72) H: 48 (84)
van de Wal et al. (2017), The Netherlands	Cross-sectional	168	<i>Mdn</i> = 67.4 (40-86)	Not reported	Partner: 168 (100.0)	Prostate	Not reported	<i>Mdn</i> = 7.5 years (0.9-20.0)	S:126 (75) S + R: 41 (25)
Wu et al. (2019), USA	Longitudinal (T1 = 6 months; T2 = 12 months)	62	<i>M</i> = 64.3 (8.4)	Not reported	Partner: 62 (100.0)	Prostate	Not reported	89.8 days (95.0)	R: 36 (52.2) S: 18 (26.1) B: 7 (10.1) R + B: 3 (4.3) S + R: 1 (1.4) WW: 1 (1.4) Missing: 3 (4.3)
Xu et al. (2019), China	Longitudinal (10 days)	54	Not reported	Not reported	Partner: 54 (100.0)	Breast	I: 22 (40.7) II:14 (25.9) III:18 (33.3)	22.1 months (19.88)	Not reported

*Note.* Treatment modality: S = Surgery; C = Chemotherapy; R = Radiotherapy; L = Lumpectomy; M = Mastectomy; M + Re = Mastectomy and Reconstruction; (U)M = Unilateral Mastectomy; (B)M = Bilateral Mastectomy; H = Hormonal therapy; B = Brachytherapy; WW = Watchful waiting





Author	Unbiased selection of cohort?	Sample size calculation ?	Adequate description of cohort?	Validated method for assessing predictor/ outcome variables?	Validated method for assessing fear of cancer recurrence?	Adequate follow-up period?	Missing data minimal?	Confounders controlled for?	Appropriate analyses?	Total score for study
Soriano et al. (2018a) Study (1)	●	○	●	●	●	N/a	●	●	●	7
Soriano et al. (2018a) Study (2)	●	○	●	●	●	●	●	●	●	8
Soriano et al. (2018b)	●	○	●	◐	●	●	●	●	●	7.5
Soriano et al. (2019)	●	○	●	●	●	●	●		●	7
van de Wal et al. (2017)	●	●	●	●	●	N/a	●	●	●	8
Wu et al. (2019)	●	○	●	●	◐	●	●	●	●	7.5
Xu et al. (2019)	●	○	○	●	◐	●	◐	●	●	6
<b>Total score for each area</b>	19.5	5	18	19.5	18	9	18	18.5	20	

Note. ● = Yes; ◐ = Unclear, Partially; ○ = No; N/a = Not applicable.

**Table 4: Main study findings**

Author, (year)	Dependent variable	Analysis	Independent variables		Significant findings
	FCR score (SD)		Non-psychosocial (demographic, clinical)	Psychosocial	
Boehmer et al. (2016)	FRQ* HSW <sup>†</sup> : 75.2 (13.6) SMW <sup>‡</sup> : 71.8 (16.5)	Multivariate logistic regression	Sexual orientation; Co- residence; Years since diagnosis; Treatment type; Survivor comorbidities; Chemotherapy; Co- residence	Caregiver use of counselling in relation to cancer diagnosis; Social support (Survivor, Caregiver); Experience of discrimination (Caregiver); FCR score (Survivor)	<i>Non-psychosocial</i> Years since diagnosis ( $\beta = -0.25^{***}$ ); Anti- oestrogen therapy ( $\beta = 0.22^{***}$ ); Survivor comorbidities ( $\beta = 0.25^{***}$ )  <i>Psychosocial</i> Caregiver and Survivor FCR: $r_2 = .29^{***}$ Social support (Caregiver) ( $\beta = -0.24^{***}$ )
Chien et al. (2018)	MAX-PC <sup>§</sup> 5.22 (1.78)	Multivariate logistic regression	Age (Patient); Religion (Patient, Partner); Employment status (Patient, Partner); Education level (Patient, Partner); Self-perceived health status (Patient); Treatment type (radiotherapy); Cancer stage; Living arrangement (Partner)	FCR score (Patient); Relationship satisfaction (Patient, Partner)	<i>Non-psychosocial</i> None.  <i>Psychosocial</i> None.
Cohee et al. (2017)	CARS** 11.794 (4-24)	Correlation; Mediation	Age (Survivors, Partners); Ethnicity; Education;	Social constraints; Cognitive processing	<i>Non-psychosocial</i> Education $r = -.164^*$

\* FRQ = Fear of Cancer Recurrence Questionnaire (88). Higher scores indicate greater level of FCR (score range 22 – 110).

† Caregivers of cancer survivors who identify as heterosexual women (HSW)

‡ Caregivers of cancer survivors who identify as sexual minority women (SMW)

§ MAX-PC = Memorial Anxiety Scale for Prostate Cancer (89). Scale consists of 18 items, four-point Likert scale. Higher scores indicative of higher anxiety.

\*\* CARS = Concerns About Recurrence Scale (90). Four items, ranging from 0-5. Higher scores indicative of greater FCR.

Author, (year)	Dependent variable		Independent variables		Significant findings
	FCR score (SD)	Analysis	Non-psychosocial (demographic, clinical)	Psychosocial	
			Religion; Comorbidities; Time since diagnosis		<i>Psychosocial</i> X (social constraints); M (cognitive processing) Indirect effect = 0.184, 95% bootstrap CI = 0.119 to 0.271. Direct effect = 0.038, $p = 0.469$ , 95% CI = -0.066 to -.142. [ $F(3,215) = 27.917, R^2 = 0.280, p < .001$ ]
Dempster et al. (2011)	CARS 13.93 (5.83)	Correlations; Regression	Age; Gender; Relationship to survivor; Months since diagnosis; Comorbidities	Anxiety; Depression; Illness perceptions: Acute/chronic timeline; Cyclical timeline; Treatment control; Emotional cause; Behavioural cause; Externalised cause; Consequences (Patient, Carer); Personal control (Patient, Carer); Illness coherence (Patient, Carer) Coping strategies (Reflection/relaxation, Positive focus, Diversion, Planning, Interpersonal)	<i>Non-psychosocial</i> Age ( $\beta = -0.171^{***}$ )  <i>Psychosocial</i> Cyclical timeline: $r = .275^{***}$ ; Consequences (Patient): $r = .306^{***}$ ; Consequences (Carer): $r = .475^{***}$ Reflection/relaxation: $r = .333^{***}$ ; Diversion: $r = .327^{***}$ ; Interpersonal: $r = .354^{***}$ Illness coherence (Carer) ( $\beta = -0.093^*$ ); Consequences (Carer) ( $\beta = 0.273^{***}$ ); Externalised cause ( $\beta = -0.124^{**}$ ) Reflection/relaxation ( $\beta = 0.165^{**}$ ); Positive focus ( $\beta = -0.107^*$ ); Interpersonal ( $\beta = 0.179^{**}$ )

Author, (year)	Dependent variable	Analysis	Independent variables		Significant findings
	FCR score (SD)		Non-psychosocial (demographic, clinical)	Psychosocial	
Graham et al. (2016)	CARS T1:13.65 (5.58) T2: 13.97 (5.59)	Hierarchical regression	Age; Gender; Relationship to survivor; Living arrangement; Months since diagnosis; Other illness/medical condition	Anxiety; Depression; IPQR-Cluster 2 versus 1*; IPQR-Cluster 3 versus 1; Coping strategies (Planning, Interpersonal, Relaxation, Positive focus)	<i>Non-psychosocial</i> None.  <i>Psychosocial</i> IPQR-Cluster 3 versus 1 ( $\beta = -0.205^*$ ); Interpersonal ( $\beta = 0.218^*$ )
Hodges & Humphris (2009)	WOC <sup>†</sup> T1: 11.77 (4.98) T2: 11.71 (5.21)	Correlations; Path analysis	Age (Patient, Carer); Gender (Patient, Carer); Relation to patient; Co-habiting status; Children; Employment status; Cancer site; Cancer stage	Anxiety; Depression; FCR score (Patient)	<i>Non-psychosocial</i> None.  <i>Psychosocial</i> Carer FCR (3 and 6 months) $r = .754^{***}$ ; Patient and carer FCR (6 months) $r = .375^{**}$ Carer distress: $r = .734^{**}$ ; ( $\beta = 0.20^{**}$ ); Patient FCR (3 months) ( $\beta = 0.18^{**}$ ); Carer FCR (3 months) ( $\beta = 0.69^*$ )
Janz et al. (2016)	Worry scale <sup>‡</sup> $N = 212$ (47.1%)	Logistic regression	Age; Ethnicity; Education level; Health status; Comorbidities; Cancer	Received enough information on risk of recurrence from health care	<i>Non-psychosocial</i>

\* IPQ Clusters: Cluster 1 = Carers have increasingly strong causal beliefs, particularly beliefs in emotional cause; Cluster 2 = Carers increasingly believe that they and the survivor understand condition, and feel over time that there will be less severe consequences for themselves and the survivor; Cluster 3 = Carers report decreasing belief in severe consequences for survivor and carer, increase in perception that condition is acute and increase in all control beliefs.

<sup>†</sup> WOC = Worry Of Cancer scale (91). Total composite score from two items used ranged from 0-20.

<sup>‡</sup> Adapted worry scale used in previous publications (92, 93). Scores  $M \geq 3$  considered “worriers”.

Author, (year)	Dependent variable	Analysis	Independent variables		Significant findings
	FCR score (SD)		Non-psychosocial (demographic, clinical)	Psychosocial	
			stage; Treatment type (Chemotherapy, Radiation, Surgery)	providers; Emotional support from health care providers;	Non-Hispanic Black ( $\beta = .053^{**}$ ); Latino (higher acculturation) ( $\beta = 3.05^{**}$ ); Latino (lower acculturation) ( $\beta = 2.96^{**}$ ); One or more comorbidities ( $\beta = 1.95^*$ ); Chemotherapy ( $\beta = 2.77^{**}$ )  <i>Psychosocial</i> None.
Kim et al. (2012)	Adapted item* -0.04 (0.99)	Correlations; Modelling analysis	Age (Survivor, Caregiver); Cancer severity	Anxiety; Quality of life (QoL): mental health and physical health (Survivor, Caregiver); FCR score (Survivor)	<i>Non-psychosocial</i> Age: $r = -.174^{***}$ ; Cancer severity ( $\beta =$ $0.197^{***}$ )  <i>Psychosocial</i> QoL Mental health (Caregiver): $r = -$ $.296^{***}$ ; Anxiety: $r = .239^{***}$ ; Survivor and Caregiver FCR: $r = .19^{***}$ ; QoL Physical health (Survivor): ( $\beta -0.127^{**}$ ); Mental health (Caregiver): ( $\beta = -0.147^{***}$ )
Maguire et al. (2017)	WOC 9.6 (5.82)	Correlations; Multiple regression	Age (Survivor, Caregiver); Gender (Caregiver); Time since diagnosis; Cancer stage; Treatment type (Surgery,	Financial stress of caring; Time caring; Social support; Loneliness; QoL (Survivor)	<i>Non-psychosocial</i> Time since diagnosis: $r = -.18^*$ ; Chemotherapy: $r = .14^*$ ; Extent of surgery: $r = -.25^{***}$

\* Adapted from (94) measure. Higher score reflects greater FCR, zero score reflects moderate levels of FCR.

Dependent variable		Independent variables			Significant findings
Author, (year)	FCR score (SD)	Analysis	Non-psychosocial (demographic, clinical)	Psychosocial	
			Chemotherapy, Radiotherapy); Relationship to survivor; Employment status		Age (Survivor) ( $b = -0.22^*$ ); Age (Caregiver) ( $b = 0.22^*$ ); Caregiver gender: ( $r = .21^*$ ); ( $b = 0.25^{***}$ ); Extent of surgery ( $b = -0.23^{***}$ )  <i>Psychosocial</i> Survivor QoL: $r = -.28^{***}$ ; Time caring: $r = .34^{***}$ ; Loneliness: $r = .27^{***}$ Financial stress of caring: ( $b = 0.20^*$ ); Time caring: ( $b = 0.37^{***}$ ); Loneliness: ( $b = 0.25^{***}$ )
Mellon et al. (2006)	FRQ 73.1 (14.1)	Correlations	None.	Family stressors; Family hardiness; Social support; Family meaning of illness; Family QoL; Somatic concerns (Patient)	<i>Non-psychosocial</i> None.  <i>Psychosocial</i> Family stressors: $r = .29^*$ ; Meaning of illness: $r = -.28^{**}$ ; QoL: $r = -.29^*$
Mellon et al. (2007)	FRQ NR	Correlations; Modelling analysis	Age (Survivor, Caregiver); Gender (Survivor, Caregiver); Ethnicity (Survivor, Caregiver); Education level (Survivor, Caregiver); Role of relationship to survivor;	Concurrent family stressors (Actor effect, Partner effect); Family hardiness; Social support; Family meaning of cancer illness (Actor effect, Partner effect); Somatic concerns; FCR score (survivor)	<i>Non-psychosocial</i> Age (Partner effect): ( $\beta = -0.52^*$ )  <i>Psychosocial</i> Concurrent family stressors: $r = .29^{**}$ ; Meaning of cancer illness: $r = -.28^{**}$ ; Survivor FCR: $r = .41^{***}$

Author, (year)	Dependent variable FCR score (SD)	Analysis	Independent variables		Significant findings
			Non-psychosocial (demographic, clinical)	Psychosocial	
			Time since diagnosis; Other health problems		Concurrent family stressors (Actor effect): ( $\beta = 0.34^{***}$ ); Family meaning of cancer illness (Actor effect): ( $\beta = -1.24^{**}$ ); Survivor vs. family caregiver: ( $\beta = -$ $4.89^{***}$ )
Mellon & Northouse (2001)	FRQ NR	Correlations	None.	Family QoL; Family stressors; Family hardiness; Family social support; Family meaning of illness; Somatic concerns; FCR score (Patient)	<i>Non-psychosocial</i> None.  <i>Psychosocial</i> Family QoL: $r = -.33^{***}$ ; Family stressors: $r = .24^{**}$ ; Patient FCR: $r = .40^{***}$ ; Family meaning of illness: $r = -.27^{**}$
Perndorfer et al. (2019)	FCRI* Spouse evening FCR:1.43	Correlations	None.	Daily protective buffering (Patient, Spouse); Intimacy; Evening FCR score (Patient, Partner)	<i>Non-psychosocial</i> None.  <i>Psychosocial</i> Protective buffering (Patient): $r = .15^{***}$ ; Protective buffering (Spouse): $r = .25^{***}$ ; Evening intimacy (Patient): $r = -.12^{***}$ ; Evening FCR score (Patient): $r = .21^{***}$

\* FCRI = Fear of Cancer Recurrence Inventory (35). Six items ranging from 0-4. Higher scores indicative of greater FCR.



Author, (year)	Dependent variable	Analysis	Independent variables		Significant findings
	FCR score (SD)		Non-psychosocial (demographic, clinical)	Psychosocial	
Soriano et al. (2018a) Study (1)	Global FCR: CARS = 3.18	Correlations; Modelling analysis	Age (Patient); Patient physical symptoms	Social Constraints (Patient, Spouse); Anxiety; Depression; Relationship quality (Patient, Spouse)	<i>Non-psychosocial</i> Age (Patient) ( $\beta = -0.028^*$ )  <i>Psychosocial</i> FCR (Patient and Spouse): $r = .53^{***}$ ; Anxiety $r = .31^*$ ; Social constraints (Spouse): ( $\beta = 0.561^*$ ); Relationship quality (Spouse): ( $\beta = 0.050^*$ )
Soriano et al. (2018a) Study (2)	FCRI = 1.51	Correlations; Modelling analysis	None.	Social Constraints (Patient, Spouse); Negative affect (Patient, Spouse); Relationship quality (Patient, Spouse); FCR score (Spouse same day)	<i>Non-psychosocial</i> None.  <i>Psychosocial</i> FCR score (Patient and Spouse): $r = .22^{***}$ ; Social constraints: $r = .27^{**}$ ; Negative affect: $r = .32^{**}$ (DV: Same day FCR): Social constraints (Spouse): ( $\beta = 0.978^{***}$ )*; Social constraints (Patient): ( $\beta = 1.088^*$ ); Negative affect (Spouse): ( $\beta = 0.496^{**}$ ) (DV: Next day FCR): Negative affect (Spouse): ( $\beta = 0.255^{**}$ ); Relationship quality (Spouse): ( $\beta = 0.091^*$ )

\* Random effects greater but still significant

Author, (year)	Dependent variable	Analysis	Independent variables		Significant findings
	FCR score (SD)		Non-psychosocial (demographic, clinical)	Psychosocial	
Soriano et al. (2018b)	FCRI Baseline* = 5 (4). T1 = 1.117 (1.754) T2 = 0.840 (1.296) T3 = 0.570 (1.483)	Modelling analysis	None.	Capitalization attempt (Spouse, Patient); Perceived partner responsiveness (Spouse); Event positivity	<i>Non-psychosocial</i> None.  <i>Psychosocial</i> T3: Capitalization attempt (Spouse) <sup>†</sup> ( $\beta = 0.488^{**}$ ); Patient capitalization attempt (Patient) <sup>23</sup> ( $\beta = -0.662^{**}$ ); Perceived partner responsiveness <sup>‡</sup> ( $\beta = -0.421^{**}$ )
Soriano et al. (2019)	FCRI 0.96 (1.78)	Correlations; Modelling analysis	None.	Threat sensitivity (Patient, Spouse); Anxiety (Patient, Spouse); FCR score (Patient)	<i>Non-psychosocial</i> None.  <i>Psychosocial</i> Patient FCR: $r = .29^{*}$ ; Anxiety (Spouse): $r = .39^{*}$ ; Threat sensitivity (Spouse): ( $\beta = 0.408^{**}$ )
van de Wal et al. (2017)	CWS <sup>§</sup> 12.6 (3.5)	Regression; Mean comparison	Age (Partner); Years a couple; Cancer history (Partner); Education level (Partner); Children; Time	FCR score (Survivor); Health-related QoL (physical, social, physical role and emotional role	<i>Non-psychosocial</i> Age: ( $\beta = -0.295^{*}$ )  <i>Psychosocial</i>

\* One week prior to diary period

†  $N = 56$  couples‡  $N = 53$  couples§ CWS = Cancer Worry Scale, stipulating a cut-off score for high FCR as  $\geq 14$

Author, (year)	Dependent variable		Independent variables		Significant findings
	FCR score (SD)	Analysis	Non-psychosocial (demographic, clinical)	Psychosocial	
			since diagnosis; Type of treatment	functioning; mental health; vitality; pain; general health)	Survivor FCR score: ( $r = .44^{***}$ ); ( $\beta = 0.304^{***}$ ) High partner FCR vs low partner FCR: Emotional role functioning ( $p = .023^*$ ); Mental health ( $p < .001^{***}$ ); Vitality ( $p = .038^*$ ); General health ( $p = .042^*$ )
Wu et al. (2019)	Cancer specific worry measure* NR	Modelling analysis	Type of treatment (Radiation, Surgery)	FCR scores at baseline and six-months (Patient, Spouse)	<i>Non-psychosocial</i> Six-month time point: Surgery ( $\beta = -0.25^{**}$ )  <i>Psychosocial</i> Six-month time point: Baseline FCR (Spouse) ( $\beta = 0.62^{***}$ ) Twelve-month time point: Six-month FCR (Spouse) ( $\beta = 0.73^{***}$ )
Xu et al. (2019)	Adapted measure† 19.82 (17.77)	Modelling analysis; Mediation analysis	None.	Illness representation; Daily Couple Communication (perceptions of positive and negative information)	<i>Non-psychosocial</i> None.  <i>Psychosocial</i> Spouses' perception of positive information: ( $\beta = -0.168^{***}$ ); Spouses'

\* (95). Mean of two responses calculated, higher scores indicated greater FCR.

† Five items adapted from prior research (96), rated on a seven-point Likert scale.

Author, (year)	Dependent variable FCR score (SD)	Analysis	Independent variables		Significant findings
			Non-psychosocial (demographic, clinical)	Psychosocial	
					perceptions of negative information: ( $\beta = 1.045^{***}$ )

*Note.* Methods: Multivariate regression models analysis (regression, mixed models and generalised linear); Modelling analysis (path analysis, structure equation modelling and actor-partner interdependence model). NR = Not Reported.

\*\*\*  $p < .001$ ; \*\*  $p < .01$ ; \*  $p < .05$

## 5 References

1. International Agency for Research on Cancer. Cancer today. France; 2018; [cited 2020 June 5]. Available from: <https://gco.iarc.fr/today/home>.
2. Cancer Research UK. Cancer statistics for the UK. London; 2010-2011 [cited 2019 July 12]. Available from: <https://www.cancerresearchuk.org/health-professional/cancer-statistics-for-the-uk>.
3. Office for National Statistics. Cancer survival in England: national estimates for patients followed up to 2017. United Kingdom. 2019 [cited 2019 July 20]. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalinengland/nationalestimatesforpatientsfollowedupto2017#interpretation-of-these-statistics>.
4. Arnold M, Rutherford MJ, Bardot A, Ferlay J, Andersson TM, Myklebust TÅ, et al. Progress in cancer survival, mortality, and incidence in seven high-income countries 1995–2014 (ICBP SURVMARK-2): a population-based study. *Lancet Oncol*. 2019;20(11):1493-505.
5. Kurtz ME, Kurtz JC, Given CW, Given BA. Depression and physical health among family caregivers of geriatric patients with cancer—a longitudinal view. *Med Sci Monit*. 2004;10(8):CR447-CR56.

6. Pitceathly C, Maguire P. The psychological impact of cancer on patients' partners and other key relatives: a review. *Eur J Cancer*. 2003;39(11):1517-24.
7. Girgis A, Lambert S, editors. *Caregivers of cancer survivors: the state of the field*. Cancer Forum; 2009.
8. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psycho-oncology*. 2010;19(10):1013-25.
9. Simard S, Savard J, Ivers H. Fear of cancer recurrence: specific profiles and nature of intrusive thoughts. *J Cancer Surviv*. 2010;4(4):361-71.
10. Lebel S, Ozakinci G, Humphris G, Thewes B, Prins J, Dinkel A, et al. Current state and future prospects of research on fear of cancer recurrence. *Psycho-oncology*. 2017;26(4):424-7.
11. Simard S, Thewes B, Humphris G, Dixon M, Hayden C, Mireskandari S, et al. Fear of cancer recurrence in adult cancer survivors: A systematic review of quantitative studies. *J Cancer Surviv*. 2013;7(3):300-22.
12. Deimling GT, Bowman KF, Sterns S, Wagner LJ, Kahana B. Cancer-related health worries and psychological distress among older adult, long-term cancer survivors. *Psycho-oncology*. 2006;15(4):306-20.

13. Koch L, Jansen L, Brenner H, Arndt V. Fear of recurrence and disease progression in long-term ( $\geq 5$  years) cancer survivors—a systematic review of quantitative studies. *Psycho-oncology*. 2013;22(1):1-11.
14. Yeo W, Kwan W, Teo P, Nip S, Wong E, Hin L, et al. Psychosocial impact of breast cancer surgeries in Chinese patients and their spouses. *Psycho-oncology*. 2004;13(2):132-9.
15. Gold M, Dunn LB, Phoenix B, Paul SM, Hamolsky D, Levine JD, et al. Co-occurrence of anxiety and depressive symptoms following breast cancer surgery and its impact on quality of life. *Eur J Oncol Nurs*. 2016;20:97-105.
16. Longacre ML, Ridge JA, Burtness BA, Galloway TJ, Fang CY. Psychological functioning of caregivers for head and neck cancer patients. *Oral Oncol*. 2012;48(1):18-25.
17. Turner D, Adams E, Boulton M, Harrison S, Khan N, Rose P, et al. Partners and close family members of long-term cancer survivors: health status, psychosocial well-being and unmet supportive care needs. *Psycho-oncology*. 2013;22(1):12-9.
18. Balfe M, O'Brien K, Timmons A, Butow P, O' Sullivan E, Gooberman-Hill R, et al. The unmet supportive care needs of long-term head and neck cancer caregivers in the extended survivorship period. *J Clin Nurs*. 2016;25(11-12):1576-86.

19. Girgis A, Lambert SD, McElduff P, Bonevski B, Lecathelinais C, Boyes A, et al. Some things change, some things stay the same: a longitudinal analysis of cancer caregivers' unmet supportive care needs. *Psycho-oncology*. 2013;22(7):1557-64.
20. Leventhal H, Meyer D, Nerenz D. The Common-Sense Representation of Illness Danger In: Rachman S, editor. *Contributions to Medical Psychology*. New York: Pergamon Press; 1980.
21. Wells A, Matthews G. *Attention and emotion: A clinical perspective*: Psychology Press; 1994.
22. Lepore SJ. A social–cognitive processing model of emotional adjustment to cancer. In: Baum A, Andersen B, editors. *Psychosocial interventions for cancer*: American Psychological Association; 2001. p. 99-116.
23. Simonelli LE, Siegel SD, Duffy NM. Fear of cancer recurrence: a theoretical review and its relevance for clinical presentation and management. *Psycho-oncology*. 2017;26(10):1444-54.
24. Lee-Jones C, Humphris G, Dixon R, Bebbington Hatcher M. Fear of cancer recurrence—a literature review and proposed cognitive formulation to explain exacerbation of recurrence fears. *Psycho-oncology*. 1997;6(2):95-105.
25. Lebel S, Maheu C, Tomei C, Bernstein LJ, Courbasson C, Ferguson S, et al. Towards the validation of a new, blended theoretical model of fear of cancer recurrence. *Psycho-oncology*. 2018;27(11):2594-601.



26. Mishel MH. Uncertainty in illness. *Image: The Journal of Nursing Scholarship*. 1988;20(4):225-32.
27. Dugas MJ, Gagnon F, Ladouceur R, Freeston MH. Generalized anxiety disorder: A preliminary test of a conceptual model. *Behav Res Ther*. 1998;36(2):215-26.
28. Ladouceur R, Dugas MJ, Freeston MH, Léger E, Gagnon F, Thibodeau N. Efficacy of a cognitive-behavioral treatment for generalized anxiety disorder: Evaluation in a controlled clinical trial. *J Consult Clin Psychol*. 2000;68(6):957.
29. Langlois F, Ladouceur R. Adaptation of a GAD treatment for hypochondriasis. *Cogn Behav Pract*. 2004;11(4):393-404.
30. Lambert SD, Girgis A, Lecathelinais C, Stacey F. Walking a mile in their shoes: anxiety and depression among partners and caregivers of cancer survivors at 6 and 12 months post-diagnosis. *Support Care Cancer*. 2013;21(1):75-85.
31. Tauber NM, O'Toole MS, Dinkel A, Galica J, Humphris G, Lebel S, et al. Effect of psychological intervention on fear of cancer recurrence: a systematic review and meta-analysis. *J Clin Oncol*. 2019.
32. Fardell JE, Thewes B, Turner J, Gilchrist J, Sharpe L, Girgis A, et al. Fear of cancer recurrence: a theoretical review and novel cognitive processing formulation. *J Cancer Surviv*. 2016;10(4):663-73.

33. LeSeure P, Chongkham-Ang S. The experience of caregivers living with cancer patients: A systematic review and meta-synthesis. *J Pers Med*. 2015;5(4):406-39.
34. Kayser K, Watson LE, Andrade JT. Cancer as a "we-disease": Examining the process of coping from a relational perspective. *Fam Syst Health*. 2007;25(4):404.
35. Simard S, Savard J. Fear of Cancer Recurrence Inventory: development and initial validation of a multidimensional measure of fear of cancer recurrence. *Support Care Cancer*. 2009;17(3):241.
36. Maheu C, Galica J. The fear of cancer recurrence literature continues to move forward: a review article. *Curr Opin Support Palliat Care*. 2018;12(1):40-5.
37. Centre for Reviews and Dissemination. Systematic Reviews: CRD guidance for undertaking reviews in healthcare 2009 [cited 2020 May 1]. Available from: <https://www.york.ac.uk/crd/SysRev/!SSL!/WebHelp/SysRev3.htm>.
38. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Ann Intern Med*. 2009;151(4):264-9.
39. Williams JW, Plassman BL, Burke J, Holsinger T, Benjamin S. Preventing Alzheimer's disease and cognitive decline. Evidence report/technology assessment. 2010;193(1):1-727.
40. Taylor PJ, Hutton P, Wood L. Are people at risk of psychosis also at risk of suicide and self-harm? A systematic review and meta-analysis. *Psychol Med*. 2015;45(5):911-26.

41. Janz N, Li Y, Beesley L, Wallner L, Hamilton A, Morrison R, et al. Worry about recurrence in a multi-ethnic population of breast cancer survivors and their partners. *Support Care Cancer*. 2016;24(11):4669-78.
42. Soriano EC, Pasipanodya EC, LoSavio ST, Otto AK, Perndorfer C, Siegel SD, et al. Social constraints and fear of recurrence in couples coping with early stage breast cancer. *Health Psychol*. 2018;37(9):874-84.
43. Soriano EC, Perndorfer C, Otto AK, Siegel SD, Laurenceau J-P. Does sharing good news buffer fear of bad news? A daily diary study of fear of cancer recurrence in couples approaching the first mammogram post-diagnosis. *Psycho-oncology*. 2018;27(11):2581-6.
44. Soriano EC, Perndorfer C, Siegel SD, Laurenceau J-P. Threat sensitivity and fear of cancer recurrence: A daily diary study of reactivity and recovery as patients and spouses face the first mammogram post-diagnosis. *J Psychosoc Oncol*. 2018.
45. Perndorfer C, Soriano EC, Siegel SD, Laurenceau JP. Everyday protective buffering predicts intimacy and fear of cancer recurrence in couples coping with early-stage breast cancer. *Psycho-oncology*. 2019;28(2):317-23.
46. Dempster M, McCorry NK, Brennan E, Donnelly M, Murray LJ, Johnston BT. Psychological distress among family carers of oesophageal cancer survivors: the role of illness cognitions and coping. *Psycho-oncology*. 2011;20(7):698-705.

47. Graham L, Dempster M, McCorry NK, Donnelly M, Johnston BT. Change in psychological distress in longer-term oesophageal cancer carers: are clusters of illness perception change a useful determinant? *Psycho-oncology*. 2016;25(6):663-9.
48. Mellon S, Northouse LL. Family survivorship and quality of life following a cancer diagnosis. *Res Nurs Health*. 2001;24(6):446-59.
49. Boehmer U, Tripodis Y, Bazzi A, Winter M, Clark M, Bazzi AR, et al. Fear of cancer recurrence in survivor and caregiver dyads: differences by sexual orientation and how dyad members influence each other. *J Cancer Surviv*. 2016;10(5):802-13.
50. Cohee AA, Adams RN, Johns SA, Von Ah D, Zoppi K, Fife B, et al. Long-term fear of recurrence in young breast cancer survivors and partners. *Psycho-oncology*. 2017;26(1):22-8.
51. Kim Y, Carver CS, Spillers RL, Love-Ghaffari M, Kaw CK. Dyadic effects of fear of recurrence on the quality of life of cancer survivors and their caregivers. *Qual Life Res*. 2012;21(3):517-25.
52. Mellon S, Northouse LL, Weiss LK. A Population-Based Study of the Quality of Life of Cancer Survivors and Their Family Caregivers. *Cancer Nurs*. 2006;29(2):120-31.
53. Mellon S, Kershaw TS, Northouse LL, Freeman-Gibb L. A family-based model to predict fear of recurrence for cancer survivors and their caregivers. *Psycho-oncology*. 2007;16(3):214-23.

54. Wu LM, McGinty H, Amidi A, Bovbjerg K, Diefenbach MA. Longitudinal dyadic associations of fear of cancer recurrence and the impact of treatment in prostate cancer patients and their spouses. *Acta Oncol.* 2019;58(5):708-14.
55. Chien C-H, Chuang C-K, Liu K-L, Wu C-T, Pang S-T, Chang Y-H. Positive and negative affect and prostate cancer-specific anxiety in Taiwanese patients and their partners. *Eur J Oncol Nurs.* 2018;37:1-11.
56. Hodges LJ, Humphris GM, Hodges LJ, Humphris GM. Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psycho-oncology.* 2009;18(8):841-8.
57. Maguire R, Hanly P, Balfe M, Timmons A, Hyland P, O'Sullivan E, et al. Worry in head and neck cancer caregivers: The role of survivor factors, care-related stressors, and loneliness in predicting fear of recurrence. *Nurs Res.* 2017;66(4):295-303.
58. van de Wal M, Langenberg S, Gielissen M, Thewes B, van Oort I, Prins J. Fear of cancer recurrence: A significant concern among partners of prostate cancer survivors. *Psycho-oncology.* 2017;26(12):2079-85.
59. Xu W, Wang J, Schoebi D. The role of daily couple communication in the relationship between illness representation and fear of cancer recurrence in breast cancer survivors and their spouses. *Psycho-oncology.* 2019;28(6):1301-7.

60. Chambers S, Girgis A, Occhipinti S, Hutchison S, Turner J, Morris B, et al. Psychological distress and unmet supportive care needs in cancer patients and carers who contact cancer helplines. *Eur J Cancer Care*. 2011;21(2):213-23.
61. Janda M, Steginga S, Dunn J, Langbecker D, Walker D, Eakin E. Unmet supportive care needs and interest in services among patients with a brain tumour and their carers. *Patient Educ Couns*. 2008;71(2):251-8.
62. Sklenarova H, Krümpelmann A, Haun MW, Friederich HC, Huber J, Thomas M, et al. When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer*. 2015;121(9):1513-9.
63. Hagedoorn M, Sanderman R, Bolks HN, Tuinstra J, Coyne JC. Distress in couples coping with cancer: a meta-analysis and critical review of role and gender effects. *Psychol Bull*. 2008;134(1):1.
64. Hodges L, Humphris G, Macfarlane G. A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Soc Sci Med*. 2005;60(1):1-12.
65. Scott JL, Halford WK, Ward BG. United we stand? The effects of a couple-coping intervention on adjustment to early stage breast or gynecological cancer. *J Consult Clin Psychol*. 2004;72(6):1122.

66. Llewellyn CD, Weinman J, McGurk M, Humphris G. Can we predict which head and neck cancer survivors develop fears of recurrence? *J Psychosom Res.* 2008;65(6):525-32.
67. Lebel S, Beattie S, Arès I, Bielajew C. Young and worried: Age and fear of recurrence in breast cancer survivors. *Health Psychol.* 2013;32(6):695.
68. Cook SA, Salmon P, Hayes G, Byrne A, Fisher PL. Predictors of emotional distress a year or more after diagnosis of cancer: a systematic review of the literature. *Psycho-oncology.* 2018;27(3):791-801.
69. Crist JV, Grunfeld EA. Factors reported to influence fear of recurrence in cancer patients: a systematic review. *Psycho-oncology.* 2013;22(5):978-86.
70. Yang Y, Wen Y, Bedi C, Humphris G. The relationship between cancer patient's fear of recurrence and chemotherapy: A systematic review and meta-analysis. *J Psychosom Res.* 2017;98:55-63.
71. Yang Y, Cameron J, Humphris G. The relationship between cancer patient's fear of recurrence and radiotherapy: a systematic review and meta-analysis. *Psycho-oncology.* 2017;26(6):738-46.
72. Maguire R, Hanly P, Drummond FJ, Gavin A, Sharp L. Expecting the worst? The relationship between retrospective and prospective appraisals of illness on quality of life in prostate cancer survivors. *Psycho-oncology.* 2018;27(4):1237-43.

73. Denlinger CS, Barsevick AM. The challenges of colorectal cancer survivorship. *J Natl Compr Canc Netw*. 2009;7(8):883-94.
74. Williams F, Jeanetta SC. Lived experiences of breast cancer survivors after diagnosis, treatment and beyond: qualitative study. *Health Expect*. 2016;19(3):631-42.
75. van de Wal M, van Oort I, Schouten J, Thewes B, Gielissen M, Prins J. Fear of cancer recurrence in prostate cancer survivors. *Acta oncologica*. 2016;55(7):821-7.
76. Johnson Vickberg SM. Fears about breast cancer recurrence: Interviews with a diverse sample. *Cancer Pract*. 2001;9(5):237-43.
77. Thewes B, Butow P, Bell ML, Beith J, Stuart-Harris R, Grossi M, et al. Fear of cancer recurrence in young women with a history of early-stage breast cancer: a cross-sectional study of prevalence and association with health behaviours. *Support Care Cancer*. 2012;20(11):2651-9.
78. Essers BA, Nieman FH, Prins MH, Krekels GA, Smeets NW, Neumann HM. Determinants of satisfaction with the health state of the facial skin in patients undergoing surgery for facial basal cell carcinoma. *Patient Educ Couns*. 2006;60(2):179-86.
79. Bergman J, Gore JL, Saigal CS, Kwan L, Litwin MS. Partnership and outcomes in men with prostate cancer. *Cancer*. 2009;115(20):4688-94.



80. Manne S, Kashy DA, Siegel S, Myers Virtue S, Heckman C, Ryan D. Unsupportive partner behaviors, social-cognitive processing, and psychological outcomes in couples coping with early stage breast cancer. *J Fam Psychol.* 2014;28(2):214.
81. Tolbert E, Bowie J, Snyder C, Bantug E, Smith K. A qualitative exploration of the experiences, needs, and roles of caregivers during and after cancer treatment: “That’s what I say. I’m a relative survivor”. *J Cancer Surviv.* 2018;12(1):134-44.
82. Park CL, Cho D, Blank TO, Wortmann JH. Cognitive and emotional aspects of fear of recurrence: predictors and relations with adjustment in young to middle-aged cancer survivors. *Psycho-oncology.* 2013;22(7):1630-8.
83. Papastavrou E, Charalambous A, Tsangari H. How do informal caregivers of patients with cancer cope: A descriptive study of the coping strategies employed. *Eur J Oncol Nurs.* 2012;16(3):258-63.
84. Corter AL, Findlay M, Broom R, Porter D, Petrie KJ. Beliefs about medicine and illness are associated with fear of cancer recurrence in women taking adjuvant endocrine therapy for breast cancer. *Br J Health Psychol.* 2013;18(1):168-81.
85. Gilbert SM, Miller DC, Hollenbeck BK, Montie JE, Wei JT. Cancer survivorship: challenges and changing paradigms. *J Urol.* 2008;179(2):431-8.
86. Houlihan NG. Transitioning to cancer survivorship: plans of care. *Oncology.* 2009;23(8).

87. Humphris GM, Ozakinci G. Psychological responses and support needs of patients following head and neck cancer. *Int J Surg*. 2006;4(1):37-44.
88. Northouse LL. Mastectomy patients and the fear of cancer recurrence. *Cancer Nurs*. 1981;4(3):213-20.
89. Roth AJ, Rosenfeld B, Kornblith AB, Gibson C, Scher HI, Curley-Smart T, et al. The memorial anxiety scale for prostate cancer: validation of a new scale to measure anxiety in men with prostate cancer. *Cancer*. 2003;97(11):2910-8.
90. Vickberg SMJ. The Concerns About Recurrence Scale (CARS): a systematic measure of women's fears about the possibility of breast cancer recurrence. *Ann Behav Med*. 2003;25(1):16-24.
91. Easterling DV, Leventhal H. Contribution of concrete cognition to emotion: Neutral symptoms as elicitors of worry about cancer. *Appl Psychol*. 1989;74(5):787.
92. Janz NK, Friese CR, Li Y, Graff JJ, Hamilton AS, Hawley ST. Emotional well-being years post-treatment for breast cancer: prospective, multi-ethnic, and population-based analysis. *J Cancer Surviv*. 2014;8(1):131-42.
93. Janz NK, Hawley ST, Mujahid MS, Griggs JJ, Alderman A, Hamilton AS, et al. Correlates of worry about recurrence in a multiethnic population-based sample of women with breast cancer. *Cancer*. 2011;117(9):1827-36.

94. Zhao L, Portier K, Stein K, Baker F, Smith T. Exploratory factor analysis of the Cancer Problems in Living Scale: a report from the American Cancer Society's Studies of Cancer Survivors. *J Pain Symptom Manage*. 2009;37(4):676-86.
95. Diefenbach MA, Miller SM, Daly MB. Specific worry about breast cancer predicts mammography use in women at risk for breast and ovarian cancer. *Health Psychol*. 1999;18(5):532.
96. Thewes B, Butow P, Zachariae R, Christensen S, Simard S, Gotay C. Fear of cancer recurrence: a systematic literature review of self-report measures. *Psycho-oncology*. 2012;21(6):571-87.

Word count = 4,707

*Chapter Two*

**The role of metacognition in fear of cancer recurrence, anxiety and depression in partners of cancer survivors**

Louise O'Rourke<sup>a</sup>

Supervised by Dr Peter Fisher<sup>a</sup>, Dr Gemma Cherry<sup>a</sup> and Dr Sophie Campbell<sup>b</sup>

<sup>a</sup>*Institute of Population Health, University of Liverpool, UK*

<sup>b</sup>*Royal Liverpool and Broadgreen University Hospitals NHS Trust, UK*

## Abstract

**Objective:** Partners of cancer survivors often report anxiety, depression and fear that their partners cancer will return, however, the psychological processes underpinning these are not well understood. The Self-Regulatory Executive Function (S-REF) model, a transdiagnostic model of emotional distress, states that maladaptive metacognitive beliefs (beliefs about thoughts) are fundamental to understanding the development and maintenance of emotional distress. This study explored whether metacognitive beliefs were associated with fear of cancer recurrence (FCR), anxiety and depression in adult partners of adult cancer survivors, after accounting for demographic variables and cancer stage. **Methods:** Eighty-eight participants completed a cross-sectional survey measuring demographic and clinical factors, anxiety, depression, FCR and metacognitive beliefs. Hierarchical regression modelling was used to examine model fit. **Results:** Regression analyses showed that metacognitive beliefs were associated with anxiety, depression and FCR and explained additional variance in anxiety, depression and FCR after controlling for age, gender, education and cancer stage. Negative metacognitive beliefs were most strongly associated with anxiety, depression and FCR in partners of cancer survivors. **Conclusions:** This is the first study to examine the fit of the S-REF model to understanding anxiety, depression and FCR experienced by adult partners of cancer survivors. Prospective research is necessary to test whether metacognitive beliefs have a causal role in anxiety, depression and FCR in this population. Intervention studies are also required in order to assess the potential efficacy of targeting and modifying negative metacognitive beliefs against traditional cognitive behavioural approaches.

**Keywords:** Anxiety, cancer survivors, depression, fear, metacognition, partners, recurrence

## 1. Background

Cancer diagnosis and treatment can be a challenging experience for survivors, as the physical and psychological impact can last well beyond completion of treatment and into the survivorship phase (1, 2). Caregivers of cancer survivors, particularly partners who are often the survivors' primary support (3), also experience adverse effects as a result of the cancer journey. Anxiety and depression are experienced by approximately 25-56% and 18-35% of caregivers respectively (4), with levels often exceeding those of cancer patients (5, 6) and community norms (7-9). A commonly reported concern is the "fear, worry, or concern about cancer returning or progressing" (10), which can be greater in caregivers than survivors (11-14) and remain stable even after treatment has been completed (12, 14). Fear of cancer recurrence (FCR) in caregivers is often associated with poorer quality of life (QoL) (15-17), loneliness (18), increased stress (15, 19) and heightened emotional distress (17, 20, 21).

Variables associated with caregiver FCR include younger age (11, 16, 17, 19, 22), cancer severity (17), treatment type (11, 12, 18, 19) and time since diagnosis (18, 19). Similar variables have been found to predict partners' anxiety and depression, including partner demographic factors (e.g., younger and female) and clinical factors, such as patients' cancer stage (23). Given the prevalence of adverse psychological effects experienced by partners, it is imperative to understand the psychological mechanisms underpinning anxiety, depression and FCR.

A variety of conceptual frameworks have been proposed to account for anxiety, depression and FCR in cancer patients and survivors, yet their applicability to caregivers is currently unknown. The Common-Sense Model (CSM, 24) is one of the more commonly cited frameworks and has received the most empirical support (25, 26). This model states that individuals create cognitive and emotional interpretations of an illness threat based on information sources currently available to them in order to make sense of, and respond to,

said threat (24, 27). However, this model does not fully account for variance in anxiety, depression and FCR in caregivers of cancer survivors, as illness perception have only been found to account for 21.5% - 33% of variance in these outcomes (22).

An alternative approach to understanding anxiety, depression and FCR in cancer patients and survivors may be the Self-Regulatory Executive Function (S-REF) model (28), a transdiagnostic model of emotional distress. In contrast to traditional cognitive theories that state that emotional distress is the consequence of dysfunctional beliefs, the S-REF model argues that distress is maintained due to beliefs about thoughts (metacognitive beliefs) and how a person responds to such beliefs. Maladaptive metacognitive beliefs activate certain patterns of thinking, known as the Cognitive Attentional Syndrome (CAS), which is characterised by three processes: i) perseverative thinking (e.g. worry, rumination); ii) attentional bias towards sources of threat (e.g., monitoring for negative thoughts and feelings) and; iii) ineffective coping strategies (e.g., avoidance, suppression and minimisation).

Positive and negative metacognitive beliefs are theorised to be the most influential in activating the CAS. Positive beliefs about the usefulness of, and need to engage, in worry (e.g., “worrying helps me to solve problems”) reinforces worry and other aspects of the CAS as a coping strategy (e.g., avoiding reminders of cancer). However, such strategies are counterproductive and maintain a sense of threat which indirectly maintains emotional distress. Negative beliefs about the danger and uncontrollability of worry (e.g., “I cannot ignore my worrying thoughts”) are hypothesised to maintain and exacerbate the use of the CAS as a coping strategy. Negative beliefs result in decreased efforts to stop worry as the person believes it is not possible to do so, and therefore act both directly and indirectly to maintain emotional distress.

Given the prevalence of anxiety, depression and FCR in partners of cancer survivors, the use of a transdiagnostic model may offer a more cost-effective and time-efficient



treatment approach, as multiple psychological difficulties can be treated simultaneously. Metacognitive beliefs are positively associated with emotional distress in various physical health populations, including chronic pain (29), chronic fatigue syndrome (30), diabetes (31), multiple sclerosis (32) and Parkinson's disease (33). Metacognitive beliefs are also significantly associated with anxiety, depression and trauma in cancer patients, with negative metacognitive beliefs demonstrating the strongest association with each outcome (34, 35). Furthermore, metacognitive therapy, an intervention based on the transdiagnostic model, leads to clinically-significant reductions in anxiety, depression, FCR and metacognitive beliefs which was maintained at 6-months follow-up (36).

Consequently, there is substantial support for the utility of the S-REF model in understanding anxiety, depression and FCR in cancer patients and survivors, however, no research has investigated the application of this model to understanding distress experienced by partners of cancer survivors. This study aimed to test the predictions of the S-REF model in partner of cancer survivors, whilst controlling for demographic and clinical variables, in order to investigate whether this model explains the maintenance of anxiety, depression and FCR in partners. It was hypothesised that:

(a) metacognitive beliefs will be positively associated with FCR, anxiety and depression in partners of cancer survivors;

(b) metacognitive beliefs will explain additional variance in FCR, anxiety and depression when controlling for demographic and clinical variables.

## **2. Method**

### **2.1 Participants**

Adult partners of adults (both aged  $\geq 18$  years of age) in the survivorship phase of cancer who were able to understand English were invited to participate. 'Survivorship' was

defined as: i) cancer diagnosis at least 6 months ago; ii) completion of acute medical treatment for cancer; iii) no diagnosed secondary cancer(s). Participants were not required to have been in a relationship with the survivor at the point of the survivor's diagnosis. All participants provided written and informed consent (Appendices E - F). The study was approved by the University of Liverpool Research Ethics Committee (Reference 3850; Appendix G).

## **2.2 Procedure**

Participants were recruited to this cross-sectional study via (i) specialist local and national cancer charity websites; (ii) cancer charity Facebook and Twitter feeds and; (iii) local cancer patient/survivor/family support groups (Appendix H). Participants ( $n = 106$ ) completed an anonymous survey measuring FCR, anxiety, depression and metacognitive beliefs, however, approximately 15 % of the sample had to be excluded as participants were partners of those diagnosed with advanced or recurrent cancer and metastasis, which did not meet the inclusion criteria. Consequently, 88 participants were included in the final sample, having completed the survey either online (via Qualtrics;  $n = 87$ ) or on paper ( $n = 1$ ), which took approximately 20-30 minutes. On completion of the survey, participants were provided with a debrief sheet (Appendix I). Participants were asked to indicate if they wished to be made aware of research findings by returning their contact details separately. Contact details were stored separately from survey responses, in a password-protected file, to ensure that specific responses could not be linked back to the participant. Participants were eligible to enter a prize draw to win one of six £25 retail vouchers upon completion of the measures.

## 2.3 Measures

### 2.3.1 Dependent variables

The 22-item Fear of Recurrence Questionnaire (FRQ) (37) was used to assess FCR (Appendix J). The scale is suitable for use with cancer patients and their partners and consists of items that assess extent of health worry, FCR triggers and concerns of significant others. Items are scored on a five-point Likert scale with anchor points of 1 (Strongly Agree) and 5 (Strongly Disagree). Responses are summed to provide a total score ranging from 22-110; higher scores indicate greater FCR. Internal consistency of the FRQ in this sample was good ( $\alpha = .89$ ).

The Hospital and Anxiety and Depression Scale (HADS) (38) was used to assess anxiety and depression (Appendix K). The HADS consists of fourteen questions assessing the presence of symptoms of anxiety ( $n = 7$ ) and depression ( $n = 7$ ) in the preceding week (Appendix K). Items are scored on a four-point scale, with options ranging from 0-3. Scores can be summed to produce a total scale score (ranging from 0-42) or subscale anxiety and depression scores (each ranging from 0-21), with higher scores reflecting higher levels of distress. A cut-off score of 11 or more for each subscale indicates clinically-significant level of anxiety or depression (38). The HADS total had good levels of internal consistency in this study ( $\alpha = .92$ ).

### 2.3.2 Independent variables

Demographic and clinical information was collected via a self-report questionnaire devised for this study (see Appendix L). Information included participant and survivor age, gender, education and employment status, relationship length, number of children, previous and current mental health treatment and experience of others known to the participant having

had cancer. Participants were also asked to provide information about the cancer survivors' diagnosis (cancer type, stage and treatment history).

The 30-item Metacognitions Questionnaire-30 (MCQ-30) (39) was used to assess metacognitive beliefs (Appendix M). The scale assesses five metacognitive belief domains: (1) positive beliefs about worry (e.g., "worrying will help me cope"); (2) negative beliefs about the uncontrollability and dangerousness of worry (e.g., "I can't stop worrying about cancer recurrence"); (3) cognitive confidence (e.g., "I don't trust my memory"); (4) beliefs about the need to control thoughts (e.g., "it's bad to have thoughts about cancer") and; (5) cognitive self-consciousness (e.g., "I monitor my mind for negative thoughts about cancer"). Items are rated on a 4-point scale (1= "definitely disagree" to 4 = "definitely agree"). Total subscale scores range from 6-24, with higher scores indicating greater levels of maladaptive metacognitive beliefs. Each subscale had good levels of internal consistency in this sample (ranging from  $\alpha = .73$  to  $\alpha = .89$ ).

The Cognitive Attentional Syndrome Scale (CAS-1) (40) is a 10-item measure, which assesses key aspects of the CAS, including worry and rumination, threat monitoring and maladaptive coping responses (Appendix N). Only items 1 – 6 were included in this study, as items 7 -10 duplicate the assessment of metacognitive beliefs. The CAS-1 had good levels of internal consistency in this study ( $\alpha = .87$ ).

## **2.4 Analysis**

Data were analysed using SPSS version 25 (Appendix O). Data were screened for normality of distribution which indicated evidence of skewness and kurtosis, therefore nonparametric statistics and bootstrapping techniques were used. Intercorrelations between predictor variables were tested with non-parametric (Spearman's Rho) statistics. Mann-Whitney tests were used to test for differences by gender, previous and current mental health

treatment and experience of others known to the participant having had cancer. Kruskal-Wallis tests were used to test for differences by education, employment status, cancer type, stage and treatment. Bonferroni corrections were used to adjust for multiple comparisons.

Three hierarchical regression analyses were used to test whether metacognitive beliefs explained additional variance in FCR, anxiety and depression respectively, in partners of cancer survivors, after controlling for demographic and clinical variables. The order of variables in the regression model was based on methodological and theoretical significance. Step 1 controlled for demographic variables (gender, education, cancer survivor's age), whilst step 2 controlled for cancer stage. The final step tested the prediction that metacognitive beliefs (MCQ-30 subscales) would contribute to FCR, anxiety and depression after controlling for demographic and clinical variables.

#### **2.4.1 Power calculation**

In order to determine sample size estimation, a priori power analysis was calculated. With an alpha ( $\alpha$ ) = .05 and power = .80, the projected sample size needed with this effect size (GPower 3.1) was approximately  $N = 135$  for regression analysis.

### **3 Results**

#### **3.1 Sample characteristics**

Table 1 outlines the sample characteristics. Of the participants who completed the survey, 68.2% were female with a mean age of 53.35 years ( $SD = 10.24$ ). The average FCR score was 88.18 ( $SD = 10.86$ ). A total of 27.3% of the sample scored above the clinical cut off for depression, whilst 52.3% scored above clinical cut off for anxiety. Only 2.3% of the sample reported using alcohol to cope with thoughts and feelings all of the time, whilst 68.2% reported that they never used maladaptive coping strategies. Approximately 15%

reported that they spent 50% of the time in the past week focusing attention on things that they find threatening (e.g., symptoms, thoughts).

**Table 1.** Sample characteristics

Demographic	N (%)	Clinical	N (%)
<i>Partner</i>		Cancer diagnosis	
Female	60 (68.2)	Bowel	17 (19.3)
Male	28 (31.8)	Prostate	12 (13.6)
		Head and neck	11 (12.5)
Education		Testicular	10 (11.4)
No qualifications	3 (3.4)	Brain	9 (10.2)
School level	39 (44.3)	Breast	9 (6.8)
Undergraduate	17 (19.3)	Hematologic	3 (3.4)
Postgraduate	29 (33.0)	Bone	2 (2.3)
		Skin	2 (2.3)
Employment		Bladder	1 (1.1)
Unemployed	22 (25.0)	Eye	1 (1.1)
Part time	21 (23.9)	Ovarian	1 (1.1)
Full time	45 (51.1)	Not specified	12 (13.6)
Children (Yes)	68 (77.3)	Cancer stage	
Experience of cancer (Yes)	68 (77.3)	0	2 (2.3)
		I	13 (14.8)
Previous MH treatment	36 (40.9)	II	11 (12.5)
Current MH treatment	24 (27.3)	III	23 (26.1)
		IV	16 (18.2)
		Not specified	23 (26.1)
		Treatment	
		Surgery	30 (28.3)
		Surgery and chemotherapy	21 (19.8)
		Surgery and radiotherapy	9 (8.5)
		Surgery, chemotherapy and radiotherapy	27 (25.5)
		Chemotherapy	9 (8.5)
		Radiotherapy	4 (3.8)
		Chemotherapy and radiotherapy	6 (5.7)

*Note.* MH treatment = Mental health treatment

Non-parametric tests indicated that female partners were more anxious than males ( $U = 516.5, p = .004, r = -.31$ ), however no differences reported in depression and FCR. There was a statistically significant difference in FCR between different levels of education ( $H(3) = 8.59, p = .035$ ). Bonferroni adjusted pairwise comparisons indicated a significant difference

between the mean rank FCR score of 54.21 for postgraduates and 33.18 for undergraduates. There was also a statistically significant difference in depression score between different levels of education ( $H(3) = 7.99, p = .046$ ). However, there were no differences between groups on depression.

There was a significant difference in FCR between and cancer stages ( $H(5) = 11.20, p = .048$ ). however, Bonferroni adjusted pairwise comparisons indicated there were no differences between groups on FCR. No significant differences were found in relation to employment status, cancer type or experience of others in network having had cancer.

### **3.2 Correlations**

Intercorrelations and descriptive statistics for independent variables and dependent variables are presented in Table 2. Cancer survivor age was negatively correlated with depression ( $r_s = -.216$ ), therefore partners in a relationship with younger survivors reported greater levels of depressive symptoms. Two metacognitive belief scales, NEG ( $r_s = .499$ ) and CSC ( $r_s = .322$ ) were positively associated with FCR. All MCQ-30 subscales were significantly positively correlated with anxiety, whilst four out of the five metacognitive beliefs domains were significantly positively correlated with depression.

**Table 2.** Descriptive statistics and Spearman's Rho correlations between the study independent variables and FCR, anxiety and depression

Variable	2	3	4	5	6	7	8	9	10	11	12	M	SD
1 Survivor age	.902* *	.646 ***	.188	.043	-.122	-.216 *	-.194	-.014	-.101	-.211	-.092	53.99	12.29
2 Partner age		.701* *	.190	-.065	-.109	-.190	-.237	-.058	-.161	-.222	-.041	53.35	10.24
3 Relationship length			.081	-.057	-.144	-.163	-.190	-.092	.042	-.183	-.134	24.76	13.15
4 Number of Children				.071	.057	-.067	.000	-.083	-.049	.007	-.136	1.95	1.53
5 FCR					.491 ***	.370 ***	.168	.499 ***	.026	.184	.322**	88.18	10.86
6 HADS-A						.691 ***	.254 *	.694 ***	.237 *	.418 ***	.396 ***	11.02	4.67
7 HADS-D							.154	.623 ***	.363 ***	.451 ***	.280 **	7.33	4.64
8 POS								.160	.030	.249* **	.287 **	10.28	4.18
9 NEG									.196	.550 ***	.560 ***	14.78	5.08
10 CC										.264 *	-.096	10.56	4.16
11 NC											.428 ***	10.73	3.69
12 CSC											-	14.78	4.15

*Note.* Relationship length = length of relationship in years, HADS-A = Anxiety, HADS-D = Depression, POS = Positive metacognitive beliefs; NEG = Negative metacognitive beliefs; CC = Cognitive confidence; NC = Need to control; CSC = Cognitive self-consciousness; \*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$

### 3.3 Metacognitive beliefs and FCR, anxiety and depression

The results of the regression analyses are outlined in Table 3. Multicollinearity was not evident between the predictor variables, as variance inflation factors were all less than 2.5 and tolerance indices ranged from 0.50 to 0.99. In the FCR model, demographic variables entered at Step 1 were not significant ( $F = .352$ ,  $df = 3, 83$ ,  $p = .788$ ). Cancer stage entered at Step 2 was also non-significant ( $F_{change} = 3.455$ ,  $df = 1,82$ ,  $p = .067$ ). After controlling for demographic and clinical variables, metacognitive beliefs accounted for an additional 33.0% of the variance in FCR ( $F_{change} = 8.247$ ,  $df = 5,77$ ,  $p = < .001$ ). The final model accounted for 38.3% of variance in FCR. Negative beliefs about the uncontrollability and danger of worry made independent contributions to the model of FCR ( $\beta = .626$ ,  $p < .001$ ).



In the anxiety model, demographic variables entered at Step 1 were significant ( $F = 7.787$ ,  $df = 3,83$ ,  $p = < .001$ ), accounting for 22.0% of the variance in anxiety. The clinical variable, cancer stage, entered at Step 2 was non-significant ( $F_{change} = 2.677$ ,  $df = 1,82$ ,  $p = .106$ ). Metacognitive beliefs were significant ( $F_{change} = 17.816$ ,  $df = 5,77$ ,  $p = < .001$ ), accounting for 40.5% of the variance in anxiety. The final model accounted for 65.0% of the variance in anxiety. There were three significant predictors in the model, gender ( $\beta = -.221$ ,  $p < 0.01$ ), survivor age ( $\beta = -.221$ ,  $p < 0.01$ ) and negative metacognitive beliefs ( $\beta = .652$ ,  $p < 0.001$ ).

In the depression model, demographic variables entered at Step 1 were significant ( $F = 6.140$ ,  $df = 3,83$ ,  $p = .001$ ), accounting for 18.2% of the variance in depression. Cancer stage entered at Step 2 were non-significant ( $F_{change} = 1.140$ ,  $df = 1,82$ ,  $p = .289$ ). Metacognitive beliefs entered in the final model, were significant ( $F_{change} = 11.979$ ,  $df = 5,77$ ,  $p = < .001$ ), accounting for 35.3% of the variance in depression. The final model accounted for 54.6% of the variance in depression. Survivor age was a significant predictor of depression ( $\beta = -.226$ ,  $p < 0.01$ ). Out of the metacognitive domains, negative beliefs about the uncontrollability and danger of worry ( $\beta = .488$ ,  $p < .001$ ) and cognitive confidence ( $\beta = .246$ ,  $p < 0.01$ ), made independent contributions to the model of depression.

**Table 3.** Summary of the final models of hierarchical regression predicting FCR, anxiety and depression

Variable	FCR model				Anxiety model				Depression model			
	$\Delta R^2$	$\beta$	<i>t</i>	Sig	$\Delta R^2$	$\beta$	<i>t</i>	Sig	$\Delta R^2$	$\beta$	<i>t</i>	Sig
Constant			6.040	.000***			2.534	.013*			.389	.698
<i>Demographics</i>	.013				.220 ***				.182 ***			
Gender		.140	1.358	0.178		-.221	-2.855	.006**		-.111	-1.262	.211
Survivor age		.016	.163	.871		-.221	-3.033	.003**		-.226	-2.721	.008**
Education		.184	1.855	.067		-.071	-.950	.345		.114	1.365	.176
<i>Clinical</i>	.040				.025				.011			
Cancer stage		.104	1.077	.285		.086	1.181	.241		.090	1.083	.282
<i>Metacognitive domains</i>	.330 ***				.405 ***				.353 ***			
MCQ-30 POS		.135	1.352	.180		.074	.982	.329		-.048	-.565	.574
MCQ-30 NEG		.626	4.932	.000***		.652	6.818	.000***		.488	4.484	.000***
MCQ-30 CC		.087	.879	.382		.090	1.202	.233		.246	2.890	.005**
MCQ-30 NC		-.234	-1.869	.065		-.050	-.533	.595		.128	1.199	.234
MCQ-30 CSC		.066	.520	.604		.017	.176	.861		-.080	-.742	.460
Model summary												
$R^2$	.383 ***				.650 ***				.546 ***			
Adjusted $R^2$	.311 ***				.609 ***				.493 ***			

Note. \*\*\*  $p < .001$ ; \*\*  $p < .01$ ; \*  $p < .05$

## 4 Discussion

This is the first study to explore the contribution of metacognitive beliefs to FCR, anxiety and depression in partners of cancer survivors. As predicted, metacognitive beliefs were positively associated with FCR, anxiety and depression in partners of cancer survivors. Furthermore, metacognitive beliefs explained additional variance in FCR, anxiety and depression when controlling for demographic and clinical variables, thus confirming the second study hypothesis.

### 4.1 Demographic and clinical characteristics

Partners in this sample reported greater levels of anxiety and depression if the cancer survivor was younger, which may be due to a greater sense of unexpectedness if a person is

diagnosed with cancer at a younger age, thus worries about the future and rumination about recurrence may be more prominent.

#### **4.2 Metacognitive beliefs and FCR, anxiety and depression**

The S-REF model has been used to explain the development and maintenance of various disorders, and different metacognitive beliefs are thought to be prominent in specific disorders. According to the model, beliefs about the usefulness of rumination lead both directly and indirectly to anxiety and depression. In Generalized Anxiety Disorder (GAD), the model gives particular importance to negative beliefs about the uncontrollability of worry and the danger of worrying (40). Similarly, the metacognitive model of depression (41, 42) suggests that depression results from the activation of perseverative negative thinking and unhelpful coping behaviours in response to sadness or negative thoughts. The model also proposes that perseverative negative thinking may detract from other aspects of cognition, and as a result may decrease confidence in one's own memory, concentration and attention (41). With regards to the theoretical understanding of FCR, it is argued that triggers, perceived risk of recurrence and illness uncertainty predict survivor FCR, whilst positive beliefs about worrying do not directly predict but act indirectly by increasing maladaptive coping (9, 43).

Out of the metacognitive beliefs that were assessed in this study, negative beliefs about the danger and uncontrollability of worry were found to be a significant predictor of FCR, anxiety and depression. This is consistent with mental health (44), chronic medical conditions (45) and general population (46), whereby negative beliefs about worry were found to be a significant contributor to variance in anxiety and depression. Similarly in the cancer literature, negative metacognitive beliefs explain additional variance in anxiety, depression and trauma in breast or prostate cancer (34), and are associated with heightened FCR in

various cancer populations (47-50). It may be that partners of cancer survivors engage in negative beliefs about the danger and uncontrollability of worry, which in turn maintains and exacerbates unhelpful cognitive processes such as worry, being more vigilant about symptoms or avoiding reminders of cancer. This results in the individual feeling unable to stop the rumination and worry, therefore the emotional distress is maintained.

In addition to negative metacognitive beliefs, cognitive confidence was also found to be a significant predictor of depression in this sample. This is consistent with the chronic medical conditions literature, whereby cognitive confidence is significantly associated with psychological and emotional distress, which is argued to negatively affect coping strategies when patients feel mentally fatigued (45). Furthermore, currently depressed individuals are reported to have lower cognitive confidence (51). Lack of cognitive confidence may be associated with increased depressive symptoms in this sample as partners may feel greater levels of stress, which could increase rigidity in thinking. Consequently, partners of cancer survivors may become reliant on unhelpful coping strategies, which exacerbates and maintains depression.

The findings reported in this study are taken from a mixed cohort with varying ranges of cancer type, stage and treatment. This would therefore suggest that it is not necessarily the content of thoughts that are problematic, but how someone responds to such thoughts that results in FCR and emotional distress. Consequently, the evidence from this study would suggest that the transdiagnostic model, S-REF model, is also applicable for partners of cancer survivors as well as cancer survivors. The findings also highlight the suitability of the use of a universal approach to treating anxiety, depression and FCR in partners of cancer survivors, instead of addressing presenting symptoms separately.

### **4.3 Study limitations**

Due to the study being cross-sectional, it is not possible to state whether maladaptive metacognitive beliefs are a consequence of FCR, anxiety and depression or a cause, because direction of causality cannot be assumed. A prospective study of the model is required in order to establish causality.

Participants self-reported their partners' diagnosis online; therefore, this could not be clinically confirmed. Approximately 15% of the initial data sample were of partners of those diagnosed with advanced or recurrent cancer and metastasis. These data had to be excluded as this did not meet the inclusion criteria.

The study reports on data taken from a small sample size consisting of a mixed cohort, and as such, the analyses are likely to be underpowered and findings difficult to generalise. Larger studies exploring metacognitive beliefs in specific cancer types are warranted to test the stability of associations of metacognitive beliefs with FCR, anxiety and depression across different tumour populations.

### **4.4 Clinical implications**

This study is the first example of the application of the S-REF model in partners of cancer survivors in order to understand the psychological mechanisms underpinning FCR, anxiety and depression. Metacognitive beliefs added to the variance explained in FCR, anxiety and depression beyond the contribution made by demographic variables and cancer stage, thus suggesting that the way in which a person responds to thoughts is significant in the development and maintenance of emotional distress. Consequently, psychological interventions that focus on modifiable factors, such as metacognitive beliefs, may be effective for this population. Targeting metacognitive beliefs when treating anxiety, depression, and FCR have indicated larger post-intervention effects in comparison to

traditional cognitive behavioural therapy (52, 53). Given that an interdependent relationship exists between emotional distress reported by cancer patients and their partners (54, 55) and similar psychological mechanisms underpin distress experienced by cancer patients, there is an argument for interventions based on this model to be delivered jointly to both cancer patient and partner. By delivering interventions based on a transdiagnostic model of emotional distress, this would offer a much more effective time-efficient approach, as difficulties could be addressed simultaneously rather than treatments delivered separately.

Future research should endeavour to strengthen the evidence base and prospectively explore the role of metacognitive beliefs in partners of cancer survivors, whilst controlling for baseline levels of FCR, anxiety, depression, clinical variables and cancer stage. Research could consider the contribution of illness perceptions, to investigate whether metacognitive beliefs continue to significantly explain additional variance in FCR, anxiety and depression when both theoretical frameworks are included in a regression model. Intervention studies are also required in order to assess the potential efficacy of targeting and modifying negative metacognitive beliefs against traditional cognitive behavioural approaches.

#### **4.5 Conclusion**

The findings from this study supports the prediction from the S-REF model that metacognitive beliefs explain additional variance in FCR and emotional distress, when controlling for demographic and clinical variables. Consequently, the S-REF model offers an alternative understanding of the psychological mechanisms involved in emotional distress in partners of cancer survivors, which may be useful for consideration in the design of future interventions. However, further research is warranted in order to build upon these findings, specifically longitudinal studies are necessary to determine a causal role for metacognitive beliefs in anxiety and depression. Intervention studies also need to evaluate the potential efficacy of metacognitive therapy in alleviating anxiety, depression, FCR experienced by

partners of cancer survivors. This study offers preliminary evidence for the utility of the S-REF model in understanding the experiences of partners of survivors, which may help to inform more targeted treatments for this population.

## 5 References

1. Williams F, Jeanetta SC. Lived experiences of breast cancer survivors after diagnosis, treatment and beyond: qualitative study. *Health Expect.* 2016;19(3):631-42.
2. Simard S, Thewes B, Humphris G, Dixon M, Hayden C, Mireskandari S, et al. Fear of cancer recurrence in adult cancer survivors: A systematic review of quantitative studies. *J Cancer Surviv.* 2013;7(3):300-22.
3. Nijboer C, Tempelaar R, Sanderman R, Triemstra M, Spruijt RJ, Van Den Bos GA. Cancer and caregiving: the impact on the caregiver's health. *Psycho-oncology.* 1998;7(1):3-13.
4. Mitchell AJ, Ferguson DW, Gill J, Paul J, Symonds P. Depression and anxiety in long-term cancer survivors compared with spouses and healthy controls: a systematic review and meta-analysis. *Lancet Oncol.* 2013;14(8):721-32.
5. Sklenarova H, Krümpelmann A, Haun MW, Friederich HC, Huber J, Thomas M, et al. When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer.* 2015;121(9):1513-9.
6. Chambers S, Girgis A, Occhipinti S, Hutchison S, Turner J, Morris B, et al. Psychological distress and unmet supportive care needs in cancer patients and carers who contact cancer helplines. *Eur J Cancer Care.* 2011;21(2):213-23.



7. Price MA, Butow PN, Costa DS, King MT, Aldridge LJ, Fardell JE, et al. Prevalence and predictors of anxiety and depression in women with invasive ovarian cancer and their caregivers. *Med J Aust.* 2010;193:S52-S7.
8. Couper JW, Bloch S, Love A, Duchesne G, Macvean M, Kissane DW. The psychosocial impact of prostate cancer on patients and their partners. *Med J Aust.* 2006;185(8):428-32.
9. Lambert SD, Girgis A, Lecathelinais C, Stacey F. Walking a mile in their shoes: anxiety and depression among partners and caregivers of cancer survivors at 6 and 12 months post-diagnosis. *Support Care Cancer.* 2013;21(1):75-85.
10. Lebel S, Ozakinci G, Humphris G, Thewes B, Prins J, Dinkel A, et al. Current state and future prospects of research on fear of cancer recurrence. *Psycho-oncology.* 2017;26(4):424-7.
11. Janz N, Li Y, Beesley L, Wallner L, Hamilton A, Morrison R, et al. Worry about recurrence in a multi-ethnic population of breast cancer survivors and their partners. *Support Care Cancer.* 2016;24(11):4669-78.
12. Wu LM, McGinty H, Amidi A, Bovbjerg K, Diefenbach MA. Longitudinal dyadic associations of fear of cancer recurrence and the impact of treatment in prostate cancer patients and their spouses. *Acta Oncol.* 2019;58(5):708-14.
13. Matthews BA. Role and gender differences in cancer-related distress: a comparison of survivor and caregiver self-reports. *Oncol Nurs Forum.* 2003;30(3):493-9.

14. Hodges LJ, Humphris GM, Hodges LJ, Humphris GM. Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psycho-oncology*. 2009;18(8):841-8.
15. Mellon S, Northouse LL, Weiss LK. A population-based study of the quality of life of cancer survivors and their family caregivers. *Cancer Nurs*. 2006;29(2):120-31.
16. van de Wal M, Langenberg S, Gielissen M, Thewes B, van Oort I, Prins J. Fear of cancer recurrence: A significant concern among partners of prostate cancer survivors. *Psycho-oncology*. 2017;26(12):2079-85.
17. Kim Y, Carver CS, Spillers RL, Love-Ghaffari M, Kaw CK. Dyadic effects of fear of recurrence on the quality of life of cancer survivors and their caregivers. *Qual Life Res*. 2012;21(3):517-25.
18. Boehmer U, Tripodis Y, Bazzi A, Winter M, Clark M, Bazzi AR, et al. Fear of cancer recurrence in survivor and caregiver dyads: differences by sexual orientation and how dyad members influence each other. *J Cancer Surviv*. 2016;10(5):802-13.
19. Maguire R, Hanly P, Balfe M, Timmons A, Hyland P, O'Sullivan E, et al. Worry in head and neck cancer caregivers: The role of survivor factors, care-related stressors, and loneliness in predicting fear of recurrence. *Nurs Res*. 2017;66(4):295-303.
20. Segrin C, Badger T, Sieger A, Meek P, Lopez AM. Interpersonal well-being and mental health among male partners of women with breast cancer. *Issues Ment Health Nurs*. 2006;27(4):371-89.

21. Soriano EC, Pasipanodya EC, LoSavio ST, Otto AK, Perndorfer C, Siegel SD, et al. Social constraints and fear of recurrence in couples coping with early stage breast cancer. *Health Psychol.* 2018;37(9):874-84.
22. Dempster M, McCorry NK, Brennan E, Donnelly M, Murray LJ, Johnston BT. Psychological distress among family carers of oesophageal cancer survivors: the role of illness cognitions and coping. *Psycho-oncology.* 2011;20(7):698-705.
23. Pitceathly C, Maguire P. The psychological impact of cancer on patients' partners and other key relatives: a review. *Eur J Cancer.* 2003;39(11):1517-24.
24. Leventhal H, Diefenbach M, Leventhal EA. Illness cognition: using common sense to understand treatment adherence and affect cognition interactions. *Cognit Ther Res.* 1992;16(2):143-63.
25. Lee-Jones C, Humphris G, Dixon R, Bebbington Hatcher M. Fear of cancer recurrence—a literature review and proposed cognitive formulation to explain exacerbation of recurrence fears. *Psycho-oncology.* 1997;6(2):95-105.
26. Fardell JE, Thewes B, Turner J, Gilchrist J, Sharpe L, Girgis A, et al. Fear of cancer recurrence: a theoretical review and novel cognitive processing formulation. *J Cancer Surviv.* 2016;10(4):663-73.
27. Hagger MS, Orbell S. A meta-analytic review of the common-sense model of illness representations. *Psychol Health.* 2003;18(2):141-84.

28. Wells A, Matthews G. Attention and emotion: A clinical perspective: Psychology Press; 1994.
29. Ziadni M, Sturgeon J, Darnall B. The relationship between negative metacognitive thoughts, pain catastrophizing and adjustment to chronic pain. *Eur J Pain*. 2018;22(4):756-62.
30. Maher-Edwards L, Fernie BA, Murphy G, Wells A, Spada MM. Metacognitions and negative emotions as predictors of symptom severity in chronic fatigue syndrome. *J Psychosom Res*. 2011;70(4):311-7.
31. Purewal R, Fisher PL. The contribution of illness perceptions and metacognitive beliefs to anxiety and depression in adults with diabetes. *Diabetes Res Clin Pract*. 2018;136:16-22.
32. Heffer-Rahn P, Fisher PL. The clinical utility of metacognitive beliefs and processes in emotional distress in people with multiple sclerosis. *J Psychosom Res*. 2018;104:88-94.
33. Fernie BA, Spada MM, Chaudhuri KR, Klingelhofer L, Brown RG. Thinking about motor fluctuations: an examination of metacognitions in Parkinson's disease. *J Psychosom Res*. 2015;79(6):669-73.
34. Cook SA, Salmon P, Dunn G, Holcombe C, Cornford P, Fisher P. A prospective study of the association of metacognitive beliefs and processes with persistent emotional distress after diagnosis of cancer. *Cognit Ther Res*. 2015;39(1):51-60.

35. Cook SA, Salmon P, Dunn G, Holcombe C, Cornford P, Fisher P. The association of metacognitive beliefs with emotional distress after diagnosis of cancer. *Health Psychol.* 2015;34(3):207.
36. Fisher PL, Byrne A, Salmon P. Metacognitive therapy for emotional distress in adult cancer survivors: a case series. *Cognit Ther Res.* 2017;41(6):891-901.
37. NORTHOUSE LL. Mastectomy patients and the fear of cancer recurrence. *Cancer Nurs.* 1981;4(3):213-20.
38. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand.* 1983;67(6):361-70.
39. Wells A, Cartwright-Hatton S. A short form of the metacognitions questionnaire: properties of the MCQ-30. *Behav Res Ther.* 2004;42(4):385-96.
40. Wells A. *Metacognitive Therapy for Anxiety and Depression* The Guilford Press. New York, NY. 2009.
41. Papageorgiou C, Wells A. An empirical test of a clinical metacognitive model of rumination and depression. *Cognitive therapy and research.* 2003;27(3):261-73.
42. Wells A. *Emotional disorders and metacognition: Innovative cognitive therapy*: John Wiley & Sons; 2002.

43. Lebel S, Maheu C, Tomei C, Bernstein LJ, Courbasson C, Ferguson S, et al. Towards the validation of a new, blended theoretical model of fear of cancer recurrence. *Psycho-oncology*. 2018;27(11):2594-601.
44. Ramos-Cejudo J, Salguero JM. Negative metacognitive beliefs moderate the influence of perceived stress and anxiety in long-term anxiety. *Psychiatry Res*. 2017;250:25-9.
45. Lenzo V, Sardella A, Martino G, Quattropani MC. A systematic review of metacognitive beliefs in chronic medical conditions. *Front Psychol*. 2019;10.
46. Spada MM, Mohiyeddini C, Wells A. Measuring metacognitions associated with emotional distress: Factor structure and predictive validity of the metacognitions questionnaire 30. *Pers Individ Dif*. 2008;45(3):238-42.
47. Butow P, Kelly S, Thewes B, Hruby G, Sharpe L, Beith J. Attentional bias and metacognitions in cancer survivors with high fear of cancer recurrence. *Psycho-oncology*. 2015;24(4):416-23.
48. Ng DWL, Kwong A, Suen D, Chan M, Or A, Ng SS, et al. Fear of cancer recurrence among Chinese cancer survivors: Prevalence and associations with metacognition and neuroticism. *Psycho-oncology*. 2019;28(6):1243-51.
49. Smith AB, Sharpe L, Thewes B, Turner J, Gilchrist J, Fardell JE, et al. Medical, demographic and psychological correlates of fear of cancer recurrence (FCR) morbidity in breast, colorectal and melanoma cancer survivors with probable clinically significant FCR

seeking psychological treatment through the ConquerFear study. *Support Care Cancer*. 2018;26(12):4207-16.

50. Thewes B, Bell ML, Butow P. Fear of cancer recurrence in young early-stage breast cancer survivors: the role of metacognitive style and disease-related factors. *Psycho-oncology*. 2013;22(9):2059-63.

51. Halvorsen M, Hagen R, Hjemdal O, Eriksen MS, Sørli ÅJ, Eisemann M, et al. Metacognitions and thought control strategies in unipolar major depression: A comparison of currently depressed, previously depressed, and never-depressed individuals. *Cognit Ther Res*. 2015;39(1):31-40.

52. Normann N, van Emmerik AA, Morina N. The efficacy of metacognitive therapy for anxiety and depression: A meta-analytic review. *Depress Anxiety*. 2014;31(5):402-11.

53. Tauber NM, O'Toole MS, Dinkel A, Galica J, Humphris G, Lebel S, et al. Effect of psychological intervention on fear of cancer recurrence: a systematic review and meta-analysis. *J Clin Oncol*. 2019.

54. Hagedoorn M, Sanderman R, Bolks HN, Tuinstra J, Coyne JC. Distress in couples coping with cancer: a meta-analysis and critical review of role and gender effects. *Psychol Bull*. 2008;134(1):1.

55. Hodges L, Humphris G, Macfarlane G. A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Soc Sci Med*. 2005;60(1):1-12.

## Appendices

**Appendix A.** Author guidelines for Psycho-Oncology journal.

### **Manuscript categories and requirements:**

- **Original Paper**

Original research papers should contain reports of new research findings that make a significant contribution to knowledge. Original papers should not exceed 4,000 words (including no more than four figures and/or tables) plus up to 40 references.

- **Reviews**

Reviews should be critical reviews of the literature, including systematic reviews and meta-analyses and should not exceed 6,000 words, excluding references. Please complete and upload a [PRISMA](#) or [AMSTAR](#) checklist for systematic reviews. Ahead of submission, all systematic reviews and meta-analyses should be pre-registered with [PROSPERO](#). The PROSPERO registration number will need to be provided at submission.

### **Preparing your submission:**

The text file should be presented in the following order:

(i) Title; (ii) a short running title of less than 70 characters; (iii) the full names of the authors; (iv) the author's institutional affiliations at which the work was carried out, (footnote for author's present address if different to where the work was carried out); (v) abstract; (vi) main text, (vii) acknowledgements, (viii) conflict of interest statement, (ix) references, (x) tables (each table complete with title and footnotes) (xi) figure legends, (xii) appendices (if relevant). Figures and supporting information should be supplied as separate files.

- **Title**

The title should be a short informative title that contains the major key words. The title should not contain abbreviations.

#### ***Authorship***

Please refer to the journal's authorship policy the Editorial Policies and Ethical Considerations section for details on eligibility for author listing.

#### ***Acknowledgements***

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

#### ***Conflict of Interest Statement***

You will be asked to disclose conflicts of interest during the submission process. See the section 'Conflict of Interest' in the Editorial Policies and Ethical Considerations section for details on what to include in this section. Please ensure that you liaise with all co-authors to confirm agreement with the final statement. The Conflict of Interest statement should be included within the main text file of your submission.

- **Abstract**

Please provide an abstract of no more than 250 words. Abstracts should be structured according to the following headings: objective, methods, results, conclusions.

- **Keywords**



Please provide up to 10 keywords and list them in alphabetical order. Please ensure that the keywords, cancer and oncology, are used for indexing purposes. Keywords should be taken from those recommended by the US National Library of Medicine's Medical Subject Headings (MeSH) browser list at <https://www.nlm.nih.gov/mesh/>.

- **Main text**

Where possible, the text should be divided into the following sections: Background, Methods (including statistical methods), Results and Discussion. All papers must include within the Discussion section a paragraph explaining the study limitations (with subtitle “study limitations”) and a paragraph explaining the clinical implications of the study (with subtitle “clinical implications”) and a paragraph covering the Conclusions.

A statement explicitly describing the ethical background to this study and any institutional or national ethical committee approval (including approval number) must be included within the manuscript.

- **References**

All references should be numbered consecutively in order of appearance and should be as complete as possible. In text citations should be superscript numbers.

For more information, please see the [Vancouver Reference Style Guide](#)

- **Tables**

Tables should be self-contained and complement, but not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and \*, \*\*, \*\*\* should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

- **Figure Legends**

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

- **Appendices**

Appendices will be published after the references. For submission they should be supplied as separate files but referred to in the text.

Further details can be accessed on the *Psycho-Oncology* website:

<https://onlinelibrary.wiley.com/page/journal/10991611/homepage/forauthors.html>

## Appendix B. Data extraction form

<b>Author:</b>					
<b>Year of publication:</b>					
<b>Title:</b>					
<b>Location:</b>					
<b>Study design</b>	Cross-sectional:				
	Longitudinal:		Follow-up length		
	Sample number				
	Sample number in analyses				
<b>Caregiver demographics:</b>	Age:	Gender:	Ethnicity:	Education:	Relationship length:
<b>Clinical and treatment characteristics of survivor</b>	Diagnosis stage:	Time since diagnosis/treatment:		Treatment type:	
<b>Main findings</b>					
<b>Study outcomes</b>					
<b>Outcomes and predictors</b>					
<b>Analyses</b>					

**Appendix C.** Email correspondence from authors (removed for confidentiality purposes)

## Appendix D. Quality assessment tool

### William's Tool: Quality assessment of observational studies

Grade each criterion as "Yes", "No", "Partially" or "Unclear".

Factors to consider when making an assessment are listed under each criterion. Where appropriate (particularly when assigning a "No", "Partially" or "Can't tell" score), please provide a brief rationale for your decision (in parentheses) in the evidence table.

Criteria marked italics are considered the most essential quality indicators for our purposes.

#### 1) Unbiased selection of the cohort?

Factors that help reduce selection bias:

- Prospective study design and recruitment of subjects
- Inclusion/exclusion criteria clearly described (especially re age, cancer diagnosis/survivorship status)
- Assessed using valid and reliable measures
- Recruitment strategy clearly described
- Relatively free from bias (selection bias might be introduced e.g., by recruitment via advertisement)

#### 2) Sample size calculated/5% difference?

Factors to consider:

- Did the authors report conducting a power analysis or describe some other basis for determining the adequacy of study group sizes for the primary outcome(s) of interest to us?
- Was the sample size sufficiently large to detect a clinically significant difference of 5% in event rates or an OR/RR increase of  $\geq 1.5$  or decrease of  $\geq 0.67$  between groups in at least one primary outcome measure of interest to us?

#### 3) Adequate description of the cohort?

Consider whether the cohort is well-characterized in terms of baseline:

- Age
- Sex
- Race
- Educational level
- Cancer type, stage other medical factors?

#### 4) Validated method for assessing predictor/outcome variables?

Factors to consider:

- Was the method used to assess predictor/outcomes variables clearly described? (Details should be sufficient to permit replication in new studies).
- Was a valid and reliable measure used to assess predictor/outcome variables? (Subjected measures based on self-report tend to have lower reliability and validity than objective measures such as clinical reports and lab findings).

#### 5) Validated method for assessing fear of cancer recurrence?

Factors to consider:

- Were primary outcomes (fear of cancer recurrence) assessed using valid and reliable measures?
- Were these measures implemented consistently across all study participants?

## 6) Adequate follow-up period?

Factors to consider:

- Minimum adequate follow-up period is X for survivorship? Check this.
- Follow-up period should be the same for all groups
- In cohort studies, length of follow-up should be the same across all groups

## 7) Missing data minimal?

Factors to consider:

- Did attrition from any group exceed 30% (Attrition is measured in relation to the time between baseline/allocation and outcome measurement. Where different numbers of patients are followed up for different outcomes, use the number followed up for the primary outcome for this calculation).
- Did attrition differ between groups by more than 10%?

## 8) Confounders controlled for?

Factors to consider:

- Did the analysis control for any baseline differences between groups?
- Does the study identify and control for important confounding variables and effect modifiers? (Confounding variables are risk factors that are correlated with the intervention/exposure and outcome and may therefore bias the estimation of the effect of intervention/exposure on outcome if unmeasured. Effect modifiers are not correlated with the intervention/exposure, but change the effect of the intervention/exposure on the outcome. Age, race/ethnicity, education and measures of SES are examples of effect modifiers and confounding variables for the exposures and outcomes of interest in this study).

## 9) Analytic methods appropriate?

Factors to consider:

- Was the kind of analysis done appropriate for the kind of outcome data?
- Dichotomous – logistic regression, survival
- Categorical – mixed model for categorical outcomes
- Continuous – ANCOVA, mixed model
- Was the analysis done on an intention-to-treat basis? (That is, was the impact of loss to follow-up [or differential loss to follow-up] assessed, e.g., through sensitivity analysis or another intent-to-treat adjustment method?)
- Was the number of variables used in the analysis appropriate for the sample size? (The statistical technique used must be appropriate to the data and take into account issues such as controlling for small sample size, clustering, rare outcomes, multiple comparison and number of covariates for a given sample size. The multiple comparisons issue may be a problem particularly when performance results on numerous cognitive measures are being compared. When assessing change on cognitive measure over time, consider whether change score should be adjusted for baseline score, and consider distribution of baseline scores and change scores).

• The multiple comparisons issue may be a problem particularly when performance results on numerous cognitive measures are being compared. When assessing change on cognitive measure over time, consider whether change score should be adjusted for baseline score, and consider distribution of baseline scores and change scores.) •

## Appendix E. Participant information sheet

v3. 08.04.2019



### Worry in partners of cancer survivors

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. Please also feel free to discuss this with your friends, relatives and GP if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Thank you for reading this.

#### 1. What is the purpose of this study?

Fear of cancer recurrence is a commonly reported concern by cancer survivors and their partners, with partners tending to worry more about the possibility of cancer returning than cancer patients do themselves. Previous research has looked into the factors that may influence fear of cancer recurrence among cancer survivors, however much less is known about partners of cancer survivors. The aim of this study is to better understand how psychological factors can contribute to worry in partners of cancer survivors.

#### 2. Why have I been chosen to take part?

You have been asked to take part, as you are a partner of someone who has had cancer. We are hoping to recruit 150 participants both online (via social media and specialist local and national cancer charity websites) and at local support groups.

#### 3. Do I have to take part?

You do not have to take part in the study. If you do decide to participate, you are free to stop completing the survey at any time without needing to provide an explanation to the research team. As the survey does not contain personal identifiable information, it is not possible to withdraw the responses that you have already submitted. The responses that you have provided may be included within the study analysis.

#### 4. What will happen if I take part?

You will be asked to complete a survey online, which will take approximately 20 minutes. The survey will consist of various questions, which will look at emotional distress, fear of cancer recurrence, and beliefs about illness and worry. The data collected from the survey will not contain any personal identifiable information, however personal data (such as a telephone number or email address) will be requested if you wish to enter a prize draw after completing the survey.

If you do wish to be entered into a prize draw to win one of six £25 high street vouchers, you will be asked to provide your name and contact details (telephone number or email address). These details will be stored separately from the questionnaire data, and will not be linked to the responses that you have provided in the survey.

The researchers involved this study are Louise O'Rourke, Trainee Clinical Psychologist and supervisors, Dr Peter Fisher, Dr Gemma Cherry and Dr Sophie Campbell.

### 5. How will my data be used?

The study will offer an optional prize draw which will require participants to provide personal information (contact details such as telephone number or email address). The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit".

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The Chief Investigator acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Dr Peter Fisher (plfisher@liverpool.ac.uk, tel.: 0151 794 4106).

Further information on how your data will be used can be found in the table below.

How will my data be collected?	Online
How will my data be stored?	On a password-protected computer
How long will my data be stored for?	10 years
What measures are in place to protect the security and confidentiality of my data?	Data will be stored securely on the University of Liverpool computer drive, on a password-protected computer. Data will not contain personal identifiable information, and participant contact details will be stored on a separate password-protected file on the University of Liverpool computer drive. Contact details will be deleted within one month of winners of the prize draw being announced.
Will my data be anonymised?	Yes
How will my data be used?	For the purpose of a Doctorate of Clinical Psychology thesis, and publication in academic journal.
Who will have access to my data?	Named researchers in the investigatory team (details are listed at the end).

Will my data be archived for use in other research projects in the future?	No
How will my data be destroyed?	After 10 years data will be disposed of confidentially and deleted from all stored locations (University of Liverpool secure networked computer drive).

#### **6. Are there any risks in taking part?**

Due to the sensitive nature of the research topic, you may find some of the questions included in the survey distressing. There will be some questions that will ask you about your mental health, specifically if you have received treatment for difficulties with low mood or anxiety. Some questions will ask you about your partner's cancer diagnosis, e.g., "Minor aches and pains of my family member remind me of his/her illness", and "I am concerned that the difficulties with my family member's illness may not be over". You can abstain from answering any questions that you may be uncomfortable with.

Should you experience any discomfort as part of the research, please speak with your GP, or contact Macmillan cancer support line on 0808 808 00 00. The Macmillan cancer support line is free of charge to phone and is open 7 days a week, from 8am – 8pm. Further details can be found on the Macmillan website (<https://www.macmillan.org.uk/information-and-support/coping/getting-support/talking-to-us/macmillan-support-line.html>). Should you wish to speak with someone when the Macmillan cancer support line is closed, the Samaritans phone line (116 123) is open 24 hours a day.

You can also search online for local NHS cancer information and support services (<https://www.nhs.uk/service-search/Cancer-information-and-support/LocationSearch/320>).

#### **7. Are there any benefits in taking part?**

There are no direct benefits in participating in this research project. However through taking part in the study, you will be contributing to current research and furthering our understanding as to why some individuals may experience greater levels of fear of cancer recurrence. This in turn may help to improve the support already available to partners of cancer survivors, through identifying psychological factors that may enhance interventions.

#### **8. What will happen to the results of the study?**

The results of the study will be used to inform academic publications, including a Doctorate in Clinical Psychology research thesis and publication in a peer-reviewed academic journal. You will be asked to indicate on the consent form if you wish to be informed of the research findings. As the data taken from the questionnaire will be anonymised, you will not be identifiable from the results.

#### **9. What will happen if I want to stop taking part?**



You can stop answering the survey questions at any time. However, as the survey does not contain personal identifiable information, it is not possible to withdraw the responses that you have already submitted. The responses that you have provided may be included within the study analysis.

#### **10. What if I am unhappy or if there is a problem?**

If you are unhappy, or if there is a problem, please feel free to let us know by contacting the Chief Investigator, Dr Peter Fisher, 0151 794 4106, and we will try to help. If you remain unhappy or have a complaint that you feel you cannot come to us with, then you should contact the Research Ethics and Integrity Office at [ethics@liv.ac.uk](mailto:ethics@liv.ac.uk). When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researchers involved, and the details of the complaint you wish to make.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

#### **11. Who can I contact if I have further questions?**

##### **Chief Investigator:**

Dr Peter Fisher

University of Liverpool, School of Psychology, Whelan Building, Liverpool, L69 3GB

Tel: 0151 794 4106

##### **Contact details of investigatory team:**

Louise O'Rourke, Trainee Clinical Psychologist [l.o-rourke@liverpool.ac.uk](mailto:l.o-rourke@liverpool.ac.uk)

Dr Gemma Cherry

Dr Sophie Campbell

## Appendix F. Consent form



### Participant consent form

Version number & date: v3 13.04.2019

Research ethics approval number:

Title of the research project: Worry in partners of cancer survivors

Name of researcher(s): Louise O'Rourke, Dr Peter Fisher, Dr Gemma Cherry, Dr Sophie Campbell

- Please tick box
1. I confirm that I have read and have understood the information sheet dated (DATE) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
  2. I understand that my participation is voluntary and that I am free to stop completing the survey at any time without giving any reason and without my rights being affected. However, as the survey does not contain personal identifiable information, it is not possible to withdraw the responses that I have already submitted. The responses that I have provided may be included within the study analysis.
  3. I understand that I will not be identified or identifiable in the report or reports that result from the research.
  4. I understand that survey data will be stored in the University of Liverpool, and members of the research team will have access to the data for up to 10 years.
  5. I agree to take part in the above study.
  6. I understand that the information I have submitted will be used to inform academic publications, including a Doctorate in Clinical Psychology research thesis and publication in a peer-reviewed academic journal.
  7. Please tick the box if you would like to receive general feedback of the study. A page at the end of the survey will ask you to provide contact details in order for us to send you the feedback.

#### Principal Investigator

Dr Peter Fisher  
 University of Liverpool  
 School of Psychology  
 Whelan Building  
 Liverpool  
 L69 3GB  
 0151 794 4106  
 plfisher@liverpool.ac.uk

#### Student Investigator

Louise O'Rourke  
 University of Liverpool  
 School of Psychology  
 Whelan Building  
 Liverpool  
 L69 3GB  
 0151 794 5530  
 l.o-rourke@liverpool.ac.uk

## Appendix G. Ethics approval letter



Central University Research Ethics Committee A

29 April 2019

Dear Dr Fisher

I am pleased to inform you that your application for research ethics approval has been approved. Application details and conditions of approval can be found below. Appendix A contains a list of documents approved by the Committee.

### **Application Details**

Reference: 3850  
 Project Title: Worry in partners of cancer survivors  
 Principal Investigator/Supervisor: Dr Peter Fisher  
 Co-Investigator(s): Miss Louise O'Rourke, Dr Gemma Cherry  
 Lead Student Investigator: -  
 Department: Psychological Sciences  
 Approval Date: 29/04/2019  
 Approval Expiry Date: Five years from the approval date listed above

The application was **APPROVED** subject to the following conditions:

### **Conditions of approval**

- All serious adverse events must be reported to the Committee ([ethics@liverpool.ac.uk](mailto:ethics@liverpool.ac.uk)) in accordance with the procedure for reporting adverse events.
- If you wish to extend the duration of the study beyond the research ethics approval expiry date listed above, a new application should be submitted.
- If you wish to make an amendment to the study, please create and submit an amendment form using the research ethics system.
- If the named Principal Investigator or Supervisor leaves the employment of the University during the course of this approval, the approval will lapse. Therefore it will be necessary to create and submit an amendment form within the research ethics system.
- It is the responsibility of the Principal Investigator/Supervisor to inform all the investigators of the terms of the approval.

Kind regards,

Central University Research Ethics Committee A

[ethics@liverpool.ac.uk](mailto:ethics@liverpool.ac.uk)

CURECA

**Appendix - Approved Documents**

(Relevant only to amendments involving changes to the study documentation)

The final document set reviewed and approved by the committee is listed below:

Document Type	File Name	Date	Version
Questionnaire	CAS OMAC version1_28_09_2015	28/09/2015	1
Evidence Of Peer Review	Louise ORourke_Approval Research Review Committe letter	27/07/2018	1
Questionnaire	Fear of Recurrence Questionnaire-family member version	18/11/2018	1
Questionnaire	Hospital Anxiety and Depression Scale	18/11/2018	1
Questionnaire	IPQ-R-English	18/11/2018	1
Questionnaire	MCQ-30	27/11/2018	1
Questionnaire	Demographic and clinical items v3	08/03/2019	3
Advertisement	Research advert LOR v3	08/04/2019	3
Participant Information Sheet	participant info sheet paper LOR 08.04.19 v2	08/04/2019	2
Participant Information Sheet	participant info sheet online LOR 08.04.19 v3	08/04/2019	3
Debriefing Material	Debrief Sheet Louise ORourke v3 08.04.2019	08/04/2019	3
Participant Consent Form	CONSENT FORM_v3 LOROURKE	13/04/2019	3
Study Proposal/Protocol	Louise ORourke Full Research Proposal v6	15/04/2019	6
Questionnaire	Survey v1	18/04/2019	1
Research Tools	Ethics reviewer comments 24.04.2019	24/04/2019	1



**D.Clin.Psychology Programme**  
 Division of Clinical Psychology  
 Whelan Building, Quadrangle  
 Brownlow Hill  
 LIVERPOOL  
 L69 3GB

Louise O'Rourke  
 Clinical Psychology Trainee  
 Doctorate of Clinical Psychology Doctorate Programme  
 University of Liverpool  
 L69 3GB

Tel: 0151 794 5530/5534/5877  
 Fax: 0151 794 5537  
[www.liv.ac.uk/dclinpsychoi](http://www.liv.ac.uk/dclinpsychoi)

27 July 2018

**RE: Exploring the psychological process underpinning fear of cancer recurrence in partners of cancer survivors**

**Trainee:** Louise O'Rourke

**Supervisors:** Dr Peter Fisher & Dr Gemma Cherry

Dear Louise,

Thank you for your response to the reviewers' comments of your research proposal submitted to the D.Clin.Psychol. Research Review Committee (letter dated 23/07/18).

I can now confirm that your amended proposal (version number 5, dated 23/07/18) meets the requirements of the committee and has been approved by the Committee Chair.

Please take this Chairs Action decision as **final** approval from the committee.

You may now progress to the next stages of your research.

I wish you well with your research project.

Dr Luna Centifanti  
 Vice-Chair D.Clin.Psychol. Research Review Committee

A member of the  
 Russell Group

Dr Laura Golding  
 Programme Director  
[l.golding@liv.ac.uk](mailto:l.golding@liv.ac.uk)

Dr Gundi Kiemle  
 Academic Director  
[gkiemle@liv.ac.uk](mailto:gkiemle@liv.ac.uk)

Dr Jim Williams  
 Joint Clinical Director  
[j.r.williams@liv.ac.uk](mailto:j.r.williams@liv.ac.uk)

Dr Beth Greenhill  
 Joint Clinical Director  
[bethg@liv.ac.uk](mailto:bethg@liv.ac.uk)

Dr Ross White  
 Research Director  
[rgwhite@liv.ac.uk](mailto:rgwhite@liv.ac.uk)

Mrs Sue Knight  
 Programme Co-ordinator  
[sknight@liv.ac.uk](mailto:sknight@liv.ac.uk)

**Appendix H. Research advert**

v3 08.04.2019



## **Worry in partners of cancer survivors**

We are looking for partners of cancer survivors to improve our understanding of worry about a partner's cancer returning.

You will be asked to complete a brief survey that should take between 20 – 30 minutes. The survey will ask you about how you think and feel about your partner's cancer returning and also about your own experiences of anxiety, low mood and worry. You will not be identified from the responses that you give in the survey and the information you do provide will remain confidential.

To find out further information, please contact:  
**Louise O'Rourke, [l.o-rourke@liverpool.ac.uk](mailto:l.o-rourke@liverpool.ac.uk)**  
**or Dr Peter Fisher, [plfisher@liverpool.ac.uk](mailto:plfisher@liverpool.ac.uk)**

Alternatively, **access the link below** to read more about the study

[https://livpsych.eu.qualtrics.com/jfe/form/SV\\_1GMAarFwMK7Wi2x](https://livpsych.eu.qualtrics.com/jfe/form/SV_1GMAarFwMK7Wi2x)

**Appendix I. Debrief sheet**

v3. 08.04.2019

**Worry in partners of cancer survivors****Participant Debrief sheet**

Thank you for participating in the present study, which examined your experiences as a partner of a cancer survivor. The study was attempting to discover more about how psychological factors can contribute to distress and worry in partners of cancer survivors. As partners are often neglected, the hope of this research is to better understand how people cope when faced with worries of their partner's cancer diagnosis.

We hope that you have found participating in the study interesting. Your survey responses are anonymous and you will not be identifiable from the results. If you did provide your contact details (telephone number or email address) in order to enter the prize draw, these details will be stored separately from the survey data and will not be linked to the responses that you have provided in the survey. If you have any questions regarding the research, please feel free to contact one of the researchers:

Louise O'Rourke, Student Investigator  
l.o-rourke@liverpool.ac.uk

Dr Peter Fisher, Chief Investigator  
plfisher@liverpool.ac.uk

Should you experience any discomfort as part of the research, please speak with your GP, or contact Macmillan cancer support line on 0808 808 00 00. Lines are open 7 days week, from 8am – 8pm. Further details can be found on the Macmillan website: <https://www.macmillan.org.uk/information-and-support/coping/getting-support/talking-to-us/macmillan-support-line.html>.

Should you wish to speak with someone urgently outside of these hours, please contact the Samaritans on 116 123.

Information can also be found on the NHS website, including links to specialist cancer support services: <https://www.nhs.uk/conditions/cancer/>.

Thank you again for your participation.

## Appendix J. Fear of Recurrence Questionnaire

### FAMILY MEMBER VERSION

#### **INSTRUCTIONS:**

The following 22 questions are designed to find out what you think about some health-related matters. There are no “right” or “wrong” answers; this is not a test but rather a questionnaire asking for your opinion.

Work at a fairly high speed through this questionnaire, and do not be concerned about whether or not your answers are consistent. It is your first impression that is desired. On the other hand, please do not be careless as it is your true impression that we want.

#### **CHECK THE ANSWER WHICH BEST TYPIFIES YOUR RESPONSE TO THE STATEMENT**

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Neutral</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
1. I think about my family member's health often.					
2. I am bothered by the uncertainty of my family member's health status.					
3. I think more about my family member's health now than before his/her illness was diagnosed.					
4. My family member has no physical concerns at this time.					
5. I worry no more about my family member's health than other people worry about their family's health.					
6. I feel there is little need to worry about my family member's future health status.					
7. I always take my family member's health into consideration when making future plans.					
8. Compared to other families where a member has this illness, I feel that I worry less than they do about health concerns.					
9. My family member's future health status is not a major concern of mine.					
10. I sometimes find myself preoccupied with my family member's physical condition.					
11. Just prior to my family member's regularly scheduled exams, my uneasiness about his/her health increases.					
12. I think no more about my family member's health presently than I did before his/her illness was diagnosed.					
13. I am not bothered by uncertainty regarding my family member's health status.					
14. I would like to feel more certain about my family member's health.					



15.	I seldom think about my family member's health.					
16.	Because of my family member's physical health, his/her future is of concern to me.					
17.	I do not worry about my family member's illness returning.					
18.	When I think about my family member's future health status, I feel some uneasiness.					
19.	Minor aches and pains of my family member remind me of his/her illness.					
20.	I feel optimistic as I focus on my family member's future.					
21.	I am concerned that the difficulties with my family member's illness may not be over.					
22.	I do not feel anxious about my family member's future when I read articles about his/her illness.					

## Appendix K. Hospital Anxiety and Depression Scale

### Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.  
Don't take too long over you replies: your immediate is best.

D	A		D	A	
		<b>I feel tense or 'wound up':</b>			<b>I feel as if I am slowed down:</b>
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		<b>I still enjoy the things I used to enjoy:</b>			<b>I get a sort of frightened feeling like 'butterflies' in the stomach:</b>
0		Definitely as much	0		Not at all
1		Not quite so much	1		Occasionally
2		Only a little	2		Quite Often
3		Hardly at all	3		Very Often
		<b>I get a sort of frightened feeling as if something awful is about to happen:</b>			<b>I have lost interest in my appearance:</b>
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		<b>I can laugh and see the funny side of things:</b>			<b>I feel restless as I have to be on the move:</b>
0		As much as I always could	3		Very much indeed
1		Not quite so much now	2		Quite a lot
2		Definitely not so much now	1		Not very much
3		Not at all	0		Not at all
		<b>Worrying thoughts go through my mind:</b>			<b>I look forward with enjoyment to things:</b>
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		<b>I feel cheerful:</b>			<b>I get sudden feelings of panic:</b>
3		Not at all	3		Very often indeed
2		Not often	2		Quite often
1		Sometimes	1		Not very often
0		Most of the time	0		Not at all
		<b>I can sit at ease and feel relaxed:</b>			<b>I can enjoy a good book or radio or TV program:</b>
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not Often	2		Not often
	3	Not at all	3		Very seldom

Please check you have answered all the questions

#### Scoring:

Total score: Depression (D) \_\_\_\_\_ Anxiety (A) \_\_\_\_\_

0-7 = Normal

8-10 = Borderline abnormal (borderline case)

11-21 = Abnormal (case)

## Appendix L. Demographic and clinical information

08.03.2019  
v3

### Clinical and Demographics Questionnaire

What is your age?   Prefer not to say

What is your gender?  Male  
 Female  
 Prefer not to say

What is the highest level of education qualification you have obtained?

No educational qualifications  School level  
 Undergraduate  Postgraduate

What is your employment status?

Full time employment  
 Part time employment  
 Unemployed

How long have you been in a relationship with your partner?

Prefer not to say

Do you and your partner have children?  Yes

No  
 Prefer not to say

If yes, how many?

Prefer not to say

What is your partner's age?

Prefer not to say

What was your partner's diagnosis?

*(Some people have reported the stage of cancer e.g., type and stage 1 – 4, recurrent cancer)*

Prefer not to say

What treatment did your partner receive?

*(Tick more than one option if applicable)*

Surgery  Chemotherapy  
 Radiotherapy  Other

Have other people in your family or extended network had cancer?

Yes  No  Prefer not to say

Have you received treatment for difficulties with anxiety and/or low mood in the past?

Yes  No  Prefer not to say

Are you currently receiving treatment for difficulties with anxiety and/or low mood?

Yes  No  Prefer not to say

## Appendix M: Metacognitions Questionnaire-30

META-COGNITIONS QUESTIONNAIRE 30*MCQ-30**Adrian Wells & Samantha Cartwright-Hatton*

This questionnaire is concerned with beliefs people have about their thinking. Listed below are a number of beliefs that people have expressed. Please read each item and say how much you generally agree with it by circling the appropriate number.

Please respond to all items, there are no right or wrong answers.

		Do not agree	Agree slightly	Agree moderately	Agree very much
1.	Worrying helps me to avoid problems in the future	1	2	3	4
2.	My worrying is dangerous for me	1	2	3	4
3.	I think a lot about my thoughts	1	2	3	4
4.	I could make myself sick with worrying	1	2	3	4
5.	I am aware of the way my mind works when I am thinking through a problem	1	2	3	4
6.	If I did not control a worrying thought, and then it happened, it would be my fault	1	2	3	4
7.	I need to worry in order to remain organised	1	2	3	4
8.	I have little confidence in my memory for words and names	1	2	3	4
9.	My worrying thoughts persist, no matter how I try and stop them	1	2	3	4
10.	Worrying helps me to get things sorted out in my mind	1	2	3	4
11.	I cannot ignore my worrying thoughts	1	2	3	4
12.	I monitor my thoughts	1	2	3	4
13.	I should be in control of my thoughts all of the time	1	2	3	4

		Do not agree	Agree slightly	Agree moderately	Agree very much
14.	My memory can misled me at times	1	2	3	4
15.	My worrying could make me go mad	1	2	3	4
16.	I am constantly aware of my thinking	1	2	3	4
17.	I have a poor memory	1	2	3	4
18.	I pay close attention to the way my mind works	1	2	3	4
19.	Worrying helps me cope	1	2	3	4
20.	Not being able to control my thoughts is a sign of weakness	1	2	3	4
21.	When I start worrying, I cannot stop	1	2	3	4
22.	I will be punished for not controlling certain thoughts	1	2	3	4
23.	Worrying helps me to solve problems	1	2	3	4
24.	I have little confidence in my memory for places	1	2	3	4
25.	It is bad to think certain thoughts	1	2	3	4
26.	I do not trust my memory	1	2	3	4
27.	If I could not control my thoughts, I would not be able to function	1	2	3	4
28.	I need to worry, in order to work well	1	2	3	4
29.	I have little confidence in my memory for actions	1	2	3	4
30.	I constantly examine my thoughts	1	2	3	4

*Please ensure that you have responded to all items – Thank You.*

*Copyright 1999: Contact A. Wells, University of Manchester, Academic Division of Clinical Psychology.*

## Appendix N: Cognitive Attentional Scale-1

OMAC study\_v1 DATE: 28.09.2015

### CAS-1

**Participant ID:** \_\_\_\_\_ **Date completed:** \_\_\_\_\_

1. How much time in the last week have you found yourself dwelling on or worrying about problems (e.g. health, family, finances)? (Circle a number below)

0	10	20	30	40	50	60	70	80	90	100
---	----	----	----	----	----	----	----	----	----	-----

None of  
the time

Half of  
the  
time

All of the  
time

2. How much time in the last week have you found yourself analysing your feelings/symptoms or questioning why did this happen to me? (Circle a number below)

0	10	20	30	40	50	60	70	80	90	100
---	----	----	----	----	----	----	----	----	----	-----

None of  
the time

Half of  
the  
time

All of the  
time

3. How much time in the last week have you been focusing attention on the things you find threatening (e.g. symptoms, thoughts, bodily checking)? (Circle a number below)

0	10	20	30	40	50	60	70	80	90	100
---	----	----	----	----	----	----	----	----	----	-----

None of  
the time

Half of  
the  
time

All of the  
time

4. How much time in the last week have you avoided activity or certain situations? (Circle a number below)

0	10	20	30	40	50	60	70	80	90	100
---	----	----	----	----	----	----	----	----	----	-----

None of  
the time

Half of  
the  
time

All of the  
time

5. How much time in the last week have you tried not to think certain thoughts? (Circle a number below)

0	10	20	30	40	50	60	70	80	90	100
---	----	----	----	----	----	----	----	----	----	-----

None of  
the time

Half of  
the  
time

All of the  
time

OMAC study\_v1 DATE: 28.09.2015

6. How much time in the last week have you used alcohol to cope with thoughts/feelings? (Circle a number below)

0	10	20	30	40	50	60	70	80	90	100
None of the time					Half of the time			All of the time		

7. How much do you believe that worrying or dwelling on thoughts is uncontrollable? (Circle a number below)

0	10	20	30	40	50	60	70	80	90	100
Not at all					Fifty percent certain			Completely certain this is true		

8. How much do you believe that worrying or dwelling on thoughts is harmful? (Circle a number below)

0	10	20	30	40	50	60	70	80	90	100
Not at all					Fifty percent certain			Completely certain this is true		

9. How much do you believe that worrying is helpful? (Circle a number below)

0	10	20	30	40	50	60	70	80	90	100
Not at all					Fifty percent certain			Completely certain this is true		

10. How much do you believe that anticipating problems will keep you safe? (Circle a number below)

0	10	20	30	40	50	60	70	80	90	100
Not at all					Fifty percent certain			Completely certain this is true		

AW/01/15

Appendix O: SPSS data output

Descriptive Statistics

	N Statistic	Minimum Statistic	Maximum Statistic	Mean Statistic	Std. Deviation Statistic	Skewness Statistic	Std. Error	Kurtosis Statistic	Std. Error
Age	54	24	74	53.35	10.243	-.245	.325	.014	.639
GenderRecode	88	1	2	1.32	.468	.794	.257	-1.401	.508
EducationRecode2	88	1	2	1.48	.502	.093	.257	-2.038	.508
RxLength	87	2	51	24.76	13.145	.236	.258	-.960	.511
PartnerAge	87	22	80	53.99	12.285	-.190	.258	-.626	.511
ChildrenRecode	88	1	3	1.24	.455	1.617	.257	1.569	.508
ChildrenNumber	88	0	7	1.95	1.531	.767	.257	.753	.508
PartnerDiagnosisRecode	88	1	14	5.92	3.791	.839	.257	-.433	.508
DiagnosisStageRecode	88	1	6	4.22	1.458	-.340	.257	-.951	.508
TreatmentRecode	88	1	14	6.27	4.645	.316	.257	-1.315	.508
TreatmentRecode2	87	1	5	3.53	1.803	-.577	.258	-1.568	.511
OthersCancerRecode	88	1	2	1.23	.421	1.324	.257	-.253	.508
PrevMHTreatmentRecode	88	1	2	1.59	.494	-.376	.257	-1.902	.508
CurrentMHTreatmentRecode	88	1	2	1.73	.448	-1.038	.257	-.944	.508
FCR_Sum	88	56	106	88.18	10.855	-.789	.257	.460	.508
MCQ_POS	88	6	22	10.28	4.177	.931	.257	-.034	.508
MCQ_NEG	88	6	24	14.78	5.075	.061	.257	-1.007	.508
MCQ_CC	88	6	24	10.56	4.160	.868	.257	.340	.508
MCQ_NC	88	6	24	10.73	3.694	1.049	.257	1.346	.508
MCQ_CSC	88	7	24	14.78	4.151	.221	.257	-.566	.508
CAS_Total	88	50	830	383.98	194.414	.257	.257	-.879	.508
CAS_MinusBeliefs	88	0	520	206.59	131.908	.390	.257	-.763	.508
HADS_A	88	1	21	11.02	4.671	-.024	.257	-.413	.508
HADS_D	88	0	19	7.33	4.638	.360	.257	-.549	.508
HADS_Total	88	1	38	18.35	8.632	.114	.257	-.349	.508
Valid N (listwise)	52								

