

**Fear of cancer recurrence in oral and oropharyngeal cancer patients:  
An investigation of the clinical encounter**

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Manuscripts

Review

Dear Dr Duijts,

Thank you for getting us feedback on the second revised version of our manuscript. Below you will find our detailed responses.

Major points.

1. I still believe that the manuscript can be shortened (a lot) to improve readability.

We have shortened it further by thoroughly editing the manuscript. The manuscript is within the limits of the journal guidelines (under 8000 words). It's currently 5995 words excluding Abstract and References and 7117 including Abstract and References.

2. Also, please check the English language carefully. A lot of errors have been made.

We have checked our manuscript again carefully and corrected any potential mistakes.

3. Finally, reviewers expressed their concerns (in their comments to the editor) about the novelty of this paper, the surplus value, and also about the fact that the results only come from interactions with one clinician with a special interest in the area. Major changes have to be made before publication is possible. Please be aware that making the requested changes will NOT guarantee acceptance.

We are surprised by these expressions of concerns at this stage of the revision process. If the reviewers feel we have not addressed their concerns (however, two reviewers have already expressed that their concerns were satisfactorily addressed and commended us on our perseverance), they should have addressed it directly and explicitly to us. We are also not clear what is meant by 'surplus value' in this context. We have repeatedly made it clear the limitation of having one clinician in our study and therefore we are not sure how else we can express this. We strongly believe in the novelty of our findings. No research study is without its limitations and we have amply and repeatedly acknowledged ours.

Minor points.

Abstract

4. Page 5, line 17: shouldn't examining the survivors' experience of this interaction be 'how survivors experience this interaction'? In line with the rest of this sentence?

We have made this suggested change.

5. Page 5, line 36: include the before consultant.

We have added 'the' before consultant.

Introduction

6. Page 6, line 20: the growing numbers requires.... is this correct? Shouldn't it be the growing numbers require or the growing number requires

We have changed it to 'growing number'.

1  
2  
3 7. Page 8, line 20: change 'death-related thoughts,' into 'death-related thoughts',  
4

5 We have made this suggested change.  
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7 8. Page 8, line 34: remove the first the  
8

9 We have made the suggested change.  
10

11 9. Page 9, line 20: regarding examining, see corresponding remark in the abstract  
12

13 We have changed it to 'examining how the survivors experience of this interaction'.  
14

15 10. Page 9, line 31: change Consultant into consultant  
16

17 We have made this suggested change.  
18

#### 19 20 Methods

21 11. Page 9, line 50 and further: this is not exactly what I meant. These patient characteristics  
22 should be described in the first part of the results section. I meant a participants or, even  
23 better, a 'study population' paragraph should be included at the beginnings of your methods  
24 section, with for example where patients were recruited, what the in- and exclusion criteria  
25 were, and so on. Subsequently, in the results section, specific data / numbers can be  
26 described.  
27

28 We have made this suggested change.  
29

30 12. Also, please check the English language of this paragraph (and throughout the manuscript). I  
31 would prefer 'the recruited participants' instead of 'the participants recruited', and 36.4%  
32 was diagnosed (instead of were).  
33

34 We have made these suggested changes.  
35

36 13. Page 11, line 36: change the team were into the team was  
37

38 We have made this suggested change.  
39

#### 40 41 42 Discussion

43 14. If you want to combine main findings and interpretation of findings, please name this  
44 section 'Interpretation of main findings'.  
45

46 We have made this suggested change.  
47

48 15. Page 22, line 26-43: this whole part can be deleted because it is just a repetition of what is  
49 already known.  
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51 We have made this suggested change.  
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3 16. Page 25, line 55. what a consultant needed manage??? needed to manage?  
4

5 We have made this suggested change.  
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7 17. Page 26, line 15. This last finding is a bit strange in this context. It seems that this paragraph  
8 has not been rewritten as a stand alone 'Implications for research and practice' paragraph,  
9 but that only some copy paste actions have been performed. It would advise to be more to  
10 the point in the implications for research and for practice. Also, hardly any implications for  
11 research are present. And, this paragraph is really long. I would advise shorten it (a lot), the  
12 same goes for the conclusion.  
13

14  
15 We think that the Associate Editor is referring to 'This last finding points to the importance of raising  
16 these fears by the health care professional during follow-up' when she says 'this last finding is a bit  
17 strange in this context'. We are not sure why the Associate Editor finds this finding strange and what  
18 'context' she is referring to. We believe that our finding is not strange at all and therefore we have  
19 not made any changes.  
20

21 With regard to length of the paragraph and also the conclusion section, we made our best to cut it  
22 further down. However, you have also asked us to expand on the research implications and  
23 therefore we have added the following 'brief' section in the interests of not making it any longer as  
24 we have been also criticised for the length of our manuscript:  
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26  
27 "In terms of research, our study was limited to one clinical setting and to one clinician with a special  
28 interest in FCR which is a limitation of our study. Future work needs to confirm our findings in other  
29 settings and with multiple clinicians. In addition, future work needs to examine whether these fears  
30 can be raised during consultation without the use of a tool such as PCI."  
31

32 Reviewer(s)' Comments to Author:

33 Reviewer: 1  
34

35 Comments to the Author

- 36 1. There is a small error on page 24 line 13: "are" should be "were" so that it reads "which may  
37 have increased the likelihood that patients' concerns were discussed."  
38

39 We have made this suggested change.  
40

41 Reviewer: 2  
42

43 Comments to the Author

- 44 1. The authors should be commended for their persistence. They seem to have addressed all  
45 the comments adequately.  
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48  
49 We thank the reviewer for their acknowledgement of our efforts.  
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## Abstract

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8 Fear of cancer recurrence (FCR) is common among individuals treated for cancer.  
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10 Explorations of how this fear is expressed within an oncology setting and responded  
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12 to are currently lacking. The aim was to investigate how head and neck cancer  
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14 survivors in follow-up consultations express FCR, how a health care professional  
15  
16 addresses recurrence fears, and examining how survivors experience this  
17  
18 interaction. We recorded the follow-up consultations of those participants who have  
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20 reported FCR as a concern on the Patient Concerns Inventory. We also conducted a  
21  
22 follow-up phone interview with the participants. We analysed the transcripts using  
23  
24 thematic analysis. Five men and six women were recruited, aged 55-87 (mean age =  
25  
26 64). Follow-up consultation analyses revealed that the consultant used 'normalising  
27  
28 FCR,' 'reassurance,' and 'offer of referral to a counsellor'. Interviews revealed  
29  
30 themes around how they coped with FCR, relevance of personal history on FCR, and  
31  
32 the impact of feeling gratitude towards the consultant on expression of FCR.  
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34 Analyses indicate that patients may feel reluctant to raise their FCR with their  
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36 clinician for fear of appearing 'ungrateful' or of damaging a relationship that is held  
37  
38 in high esteem. Findings indicate the initiation of FCR with patients can be beneficial  
39  
40 for patient support.

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48 Keywords: fear of cancer recurrence; consultations; head and neck cancer;  
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50 communication; emotional regulation  
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## Introduction

End of cancer treatment and attempting to return to normal life can bring many challenges for cancer survivors. Survivors often have to cope with numerous ongoing concerns such as lingering side effects and late treatment sequelae (Stein et al., 2008), changing work and social roles (Zebrack, 2000), return to work issues (Taskila and Lindbohm, 2007), and communication difficulties within the family (Northouse et al., 2000). The growing number of cancer survivors requires those health care professionals assisting various aspects of the care of the survivors to be familiar with, and open to, discussing issues of concern to patients and their families.

A recent comprehensive review showed that adult survivors of many cancer types commonly report fears about cancer returning (Simard et al., 2013). The review found that fear of cancer recurrence (FCR) defined recently by an expert panel as 'fear, worry, or concern about cancer returning or progressing' (Lebel et al., 2016) was 'frequently identified as the major concern or one of the top five greatest concerns' (p. 303). Moreover, these fears do not reduce with time, with 18 of the 22 longitudinal studies showing no change over the periods assessed (which ranged from 3 months to 6 years). They are also strongly related to lower global quality of life or wellbeing and increased 'unmet needs'.

Patient experience of physical symptoms following the completion of treatment can be particularly difficult, with physical symptoms often related to increased FCR (Simard et al., 2013). In addition, qualitative evidence shows that survivors find the upcoming medical appointments with the healthcare team particularly distressing which triggers FCR (Mutsaers et al., 2016). The cancer survivor, contrary to initial conjecture, may not find a check-up (e.g., ultrasound) as

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2  
3 reassuring as the health professional expects (Thewes et al., 2012). Hence, the  
4  
5 patient's FCR may increase (Lee-Jones et al., 1997). Follow-up appointments often  
6  
7 involve a physical exam or some form of screening (e.g., mammography, palpation  
8  
9 for neck nodes) which are met with trepidation over what the tests may reveal, and  
10  
11 the anticipation of relief when the results do not indicate recurrence (McGinty et al.,  
12  
13 2016). As Arora (Arora, 2003) shows in a review of the literature, the health care  
14  
15 professionals' communication behaviour (e.g., offer of choice of treatment) with  
16  
17 survivors is an important influence on outcomes such as patient satisfaction,  
18  
19 adherence, anxiety, and psychological distress. Hence, clinical services are obligated  
20  
21 to ensure good communication within the clinic setting when interacting with  
22  
23 patients so that clinicians have the opportunity to identify and manage these fears.  
24  
25 Another recent systematic review highlighted FCR as a key unmet need for  
26  
27 haematological cancer patients (Swash et al., 2014), thus highlighting the need to  
28  
29 investigate beyond the common cancers and explore FCR levels and predictors in  
30  
31 other patient groups.  
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39 In a recent study by Custers et al., (Custers et al., 2017), mediational analyses  
40  
41 showed that internal cues such as feeling sick and bodily sensations as well as  
42  
43 external cues such as cancer-related media news and contact with health  
44  
45 professionals increased FCR which in turn resulted in limited planning for future and  
46  
47 body checking. Qualitative investigation of these fears show that intrusive thoughts,  
48  
49 distress, and impact on functioning are common features of FCR as well as features  
50  
51 such as 'death-related thoughts', and 'belief that the cancer will return' (Mutsaers et  
52  
53 al., 2016). To our knowledge, no qualitative study examined how the expression of  
54  
55 FCR took place in an oncology setting and how this was addressed.  
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3           Communication between patients and health professionals in offering  
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5 improved cancer care is crucial. In the domain of fear of progression which is a  
6  
7 concept often used interchangeably with FCR, there is some evidence showing that  
8  
9 the way in which the medical encounter takes place and information offered can  
10  
11 have an impact on these fears (Gross et al., 2015). In Gross et al's study (Gross et al.,  
12  
13 2015), interruptions during the initial medical encounter caused a lower decrease in  
14  
15 fear of progression from the initial encounter to the 3-day follow-up. In addition,  
16  
17 those patients who found the information provided comprehensible at the initial  
18  
19 encounter, had subsequently reduced fear of progression.  
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24           The aim of this study was to investigate how head and neck cancer survivors  
25  
26 express FCR in follow-up consultations, how a health care professional addresses  
27  
28 recurrence fears, and examining how the survivors experience of this interaction in a  
29  
30 follow-up interview. Specifically, we aimed to answer the following questions:  
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- 33           1. Is the FCR issue expressed in the consultation? And if so, who elicits the  
34  
35 presentation of this fear?  
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- 38           2. How does the consultant manage the patient's FCR, should it arise in the  
39  
40 consultation?  
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- 43           3. What factors might be responsible for some patients to focus intensely on  
44  
45 FCR? How do they self-manage this fear and any triggers for it?  
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- 48           4. How do survivors respond to the discussion around FCR? Specifically, did the  
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50 discussion ease their concerns and abate their anxiety?  
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## Method

All recruited participants were patients of one clinician (SR) attending his outpatient review clinic following primary cancer treatment in a consecutive manner. Patients were required to be over the age of 18, currently disease free, and to have completed treatment at least three months previously (Mean = 38.1 months, SD = 38.4 months).

### *Procedure*

This study received ethical approval from both the National Research Ethics Service and local research governance at participating sites. Patients who visit the follow-up clinic are routinely invited to complete the Patient Concerns Inventory (PCI; (Rogers et al., 2009)) before their outpatient clinic appointment as a feature of standard care. The PCI is a measure developed from clinical case material that highlighted the phenomena of patients feeling reluctant to discuss psychosocial concerns, such as FCR, with their health care professionals (Humphris and Ozakinci, 2006) and was developed as a tool to detect patient concerns in people with head and neck cancer (Rogers et al., 2009). It consists of 57 items that patients are invited to select if applicable to help guide their consultation. Sample items include appetite and fatigue/tiredness along with FCR, and is presented in either a pencil and paper format or computer touch screen.

For the recruitment period, we checked individual PCI responses after each patient completion and identified those patients who selected 'fears of cancer recurrence' as a concern to discuss with their clinician. These patients were then approached by the researcher (BS) prior to their consultation to consider volunteering as a study participant. On consent, the patient's consultation was

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2  
3 audio-recorded and a follow-up interview, either via telephone or in person, was  
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5 arranged. Follow-up interviews were conducted within 48 hours of outpatient  
6  
7 appointment and followed a semi-structured format. The interview focused on the  
8  
9 following broad topics:

- 12 • Presence of patient ongoing concerns;
- 14 • The impact of these concerns on everyday life;
- 17 • The frequency of FCR and intensity of cancer recurrence related thoughts;
- 20 • Whether the patient believed that their clinical team was aware of their FCR  
21 and recurrence related thoughts;
- 24 • Whether the consultation had explicitly focused on their FCR and whether  
25 this focus had been helpful in alleviating fears;
- 29 • Whether any continuing support been offered

#### 33 *Data Analysis*

36 Questions 1 and 2 were addressed by an analysis of consultation recordings,  
37  
38 whereas questions 3 and 4 were mainly addressed through analyses of follow-up  
39  
40 interview data. Audio-recordings of both the consultations and interviews were  
41  
42 transcribed verbatim. All data were analysed using a thematic analysis approach  
43  
44 (Braun and Clarke, 2006) with a further content analysis employed within the  
45  
46 transcripts of the consultations. Thematic analysis is a qualitative approach that has  
47  
48 often been utilised within psycho-oncology research (e.g., (Nilsson et al., 2013,  
49  
50 Denford et al., 2011)) and involves the identification of themes that emerge as  
51  
52 important for the description of the phenomenon in question (Daly et al., 1997). In  
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54 order for themes to be identified, a process of reading, note taking, then re-reading  
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3 the data in order to begin to recognise patterns within the data must take place  
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5 (Rice and Ezzy, 1999). Emergent themes, then, become the basis of the analysis.  
6  
7

8 All transcripts were analysed in depth by two researchers independent of  
9  
10 each other (BS and GO). The resulting framework was discussed at length and a  
11  
12 consensus agreed. Validation was achieved through extensive discussion with a  
13  
14 third team member (NHW).  
15  
16

17 In quotes below, the first number denotes the participant number followed  
18  
19 by gender (F/M), age of the participant, and whether it is the consultation (C) or the  
20  
21 follow-up interview (I).  
22  
23

## 24 Results

### 25 **Study Population**

26 In total, five males and six females were recruited. All were aged between 55  
27  
28 and 87 (mean age = 64). All participants had been diagnosed and actively treated for  
29  
30 head and neck cancer. Primary tumour sites were most commonly oral cavity and  
31  
32 pharyngeal. 36.4% of the sample was diagnosed with low disease severity (Stages 1  
33  
34 and 2), with 63.6% of the sample being diagnosed with high disease severity (Stages  
35  
36 3 and 4). All had completed treatment and were currently disease free at the time  
37  
38 of study recruitment. The most common treatments were combined surgery and  
39  
40 radiotherapy (55%), followed by chemoradiotherapy (27%). We had audio  
41  
42 recordings from all consultations but one and interview recordings from all  
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44 interviews but one (due to technical difficulties, two recordings were not available).  
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### *Analysis of Consultation Recordings*

In all consultations but one, it was the consultant who brought up the issue of FCR, presumably prompted by their access to the PCI responses. In eight of the cases, referral for emotional support was made. On one occasion, the participant was already seeing a counsellor. On two occasions, the participant accepted the offer of referral. On other occasions, the participants did not want any referral, citing other sources of support (e.g., carer) or downplaying the extent of the impact of the fears on them. Bringing up the FCR usually happened following a general, broad opening, which was followed by a discussion around physical symptoms experienced by the patient. The consultant, then, preceded to enquire about the frequency of these fears as well as what triggers them. In most cases, the consultant used several strategies to help patients cope with their FCR.

*Consultant: "I noticed on the, on the computer system you mentioned about the worry about the cancer coming back, how often do you notice that, what's...?"*

*(3M62C)*

*3M62C: Every day.*

*Consultant: Every day, what makes you notice that?*

*3M62C: Sorry...?*

*Consultant: What makes you notice it?*

*3M62C: Erm mostly when I open my mouth and I feel things, you know, erm...it's something that doesn't go away."*

### **NORMALISING THE FEAR**

The consultant normalised the fears as something that can be expected after such a diagnosis and treatment.

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*'..Well, it's understandable, it's a healthy thing to be' (4F60C)*

*'... I mean it's a natural concern, isn't it? You've had cancer, you look like you're cured, that's what we expect, water's passing under the bridge now. Erm that and that's fantastic but there can still be that niggle, can't there?'* (3M62C)

#### REASSURANCE

The consultant reassured patients by various means. First, he used information about the duration since diagnosis and treatment as providing reassurance.

*'.. but 3 years has gone by and if there was going to be a problem, near enough invariably, as sure as eggs are eggs by now, we'd have found it'.* (2M55C)

*'So the chance of it coming back now is really, really, really, really, very very very small'* (2M55C)

The consultant also reassured by indicating how head and neck cancer compares favourably with other cancer sites with regard to recurrence. Frequently, this comparison was made with breast cancer.

*'Because, you know, in many ways, you know, if you were gonna run into trouble, we'd have, we'd have had it by now. Now I'm looking at a patient who's cured. It's not like prostate cancer that can come back or breast cancer that can come back years and years down the line, that's not normally the way it is. If it's going to be a problem, we know within a year, 18 months'.* (3M62C)

The consultant almost always conducted a physical exam and used that as an opportunity to reassure patient with regard to any symptoms. Despite using techniques to reassure, the consultant expressed the need for vigilance and caution.

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2  
3 *'We just need to be very vigilant' (6M70C)*  
4

5 Furthermore, the consultant offered a discussion around when the next  
6  
7 follow-up should be. This revolved around how the frequency of follow-up  
8  
9 appointments would potentially impact FCR. The consultant often emphasised that  
10  
11 the patient could always call him if there was any concern with regard to fears about  
12  
13 cancer coming back (e.g., triggered from a symptom experience).  
14  
15

16  
17 *".. So, let's go for six months and I'll get... and I can always, you can, you can always*  
18  
19 *bring it forward by phone... (3M62C)"*  
20

#### 21 OFFERING THE POSSIBILITY OF REFERRING TO A COUNSELLOR 22

23  
24 The consultant often offered this service facility and on two occasions, this  
25  
26 was accepted.  
27

28  
29 *"I still feel that probably getting somebody who's experienced with looking*  
30  
31 *after patients with this would be helpful to you. " (5F63C)*  
32

33  
34 *"Actually I really believe it would be...it's got the possibility to ease my mind"*  
35  
36 *(5F63C)*  
37

#### 38 *Analysis of Patient Interviews* 39

40 The analysis of the participants' interviews revealed a range of themes  
41  
42 relating to patients' FCR and key barriers for these fears to be expressed and  
43  
44 managed.  
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#### 48 49 TRIGGERS OF FCR 50

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52 Participants identified a series of triggers for their fears, some of which were  
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54 directly related to sensations within their bodies while others were related to  
55  
56 external events.  
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3 When patients noticed potential symptoms of a recurrence, this immediately  
4  
5 created concerns. If an area of the body that had been previously affected by  
6  
7 cancer, generally the throat or the mouth, became sore or changes of any kind were  
8  
9 observed, then this was experienced as a strong trigger for FCR.  
10  
11

12 *“I did have a concern, um a few months back where I found some swollen glands in*  
13 *me neck” (2M55I)*  
14  
15

16  
17 While symptoms that were directly related to the previous cancer were  
18  
19 related to FCR, so were somatic concerns more generally. Some participants  
20  
21 associated any changes or pains within their bodies as being potential indicators of a  
22  
23 recurrence, regardless of how common or unrelated the perceived symptom might  
24  
25 be.  
26  
27

28  
29 *“It might be a little pain to everybody else but I’m aware” (7M55I)*  
30  
31

32 The presence of external reminders of cancer, notably charity advertisements  
33  
34 on the television or radio, meant that participants were no longer able to distract  
35  
36 themselves actively to forget about their previous illness or to concentrate on other  
37  
38 things as many described trying to do.  
39

40  
41 *“There’s a lot on TV today... It just, you’ve forgotten about it and then, suddenly it*  
42 *registers again” (4F60I)*  
43  
44

45 Follow-up appointments were either seen in a strongly positive manner or  
46  
47 were deemed something to be feared. In either case, knowing that they were going  
48  
49 to see their clinician imminently meant that participants were unable to avoid their  
50  
51 fears and the possibility that they would soon be given the bad news that their  
52  
53 cancer had returned.  
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3 *"I am terrified for coming seeing you, I'm actually sitting here terrified to walk*  
4  
5 *through that door" (3M62I)*  
6

#### 7 8 COPING WITH FCR

9  
10 A commonly reported method of coping with FCR was distraction. A variety  
11  
12 of methods were employed, all with the fundamental aim of providing the mind with  
13  
14 something more positive to focus on than the possibility of a cancer recurrence.  
15

16  
17 *"I invested in my letter, which I'm writing, or painting, it fills the habit" (7M55I)*  
18

19  
20 Some participants felt that their ability to cope, or not, with their diagnosis  
21  
22 was in part due to their personality. Some participants believed that their underlying  
23  
24 personality meant that they were more able to keep positive despite their fears,  
25  
26 while others identified their FCR as being inevitable given their natural propensity to  
27  
28 worry.  
29

30  
31 *"I think I've got a positive attitude anyway" (6M70I)*  
32

33  
34 Having a confidante was often perceived to be a vital aspect of being able to  
35  
36 cope with, or manage, fears.  
37

38  
39 *"If you're on your own and you go home, and you sit there all on your own, no one to*  
40  
41 *talk to... that is a different thing to me, I have someone to talk to" (10F74I)*  
42

#### 43 44 RELEVANCE OF PERSONAL HISTORY

45  
46 A person's background and the prior knowledge and experiences that they  
47  
48 brought to their cancer experience was felt to strongly impact upon how cancer was  
49  
50 perceived by the individual. Having a family history of cancer, particularly, where a  
51  
52 family member had passed away as a result of the disease, was believed to  
53  
54 compound any fears about the cancer returning.  
55  
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1  
2  
3 *“watching, erm, me Dad getting eaten away by cancer. And seeing the way he went*  
4  
5 *and having the fear of if... am I gonna go down that road?” (4F60I)*  
6  
7

8 The person’s own previous experiences of cancer also fed into how strongly  
9  
10 the prospect of a recurrence was perceived to be a real fear. In cases where  
11  
12 treatment was experienced as traumatic or, in the case of one participant, they had  
13  
14 an on-going co-morbid diagnosis, the fear that the cancer may return was keenly  
15  
16 felt.  
17

18  
19 *“the tracheotomy is the worst thing you could have” (10F74I)*  
20  
21

22 For one participant in particular, the presence of past difficulties (alcohol  
23  
24 dependency) created a negative comparison regarding the amount of support  
25  
26 available for concerns relating to their cancer. The participant felt that the amount  
27  
28 of support available to them as a cancer patient was less than is available for other  
29  
30 conditions he had. The consequence was a concern that they would be inadequately  
31  
32 supported, should their cancer return.  
33  
34

35  
36 *“Because I suffer with alcoholism, the amount of help I receive through that is*  
37  
38 *enormous compared to [this]” (7M55I)*  
39

#### 40 THE CAUSES OF PARTICIPANTS’ FEARS

41  
42 Some specific triggers and correlates to the presence of FCR have been  
43  
44 highlighted. Having to cope again with the shock of a diagnosis and the difficulties of  
45  
46 treatment should the cancer return was identified as a concern. Participants felt  
47  
48 unsure as to whether they were physically and emotionally strong enough to repeat  
49  
50 their previous experience of cancer.  
51  
52

53  
54  
55 *“I feel as though... I don’t know what I’d do if it reappeared” (8F50I)*  
56  
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2  
3 Many expressed the worry that if the cancer returned, it would be  
4  
5 untreatable and that the diagnosis would be terminal.  
6

7 *“the worst thing you can have said you is that, if it comes back there’s nothing we*  
8  
9 *can do about it” (10F74I)*  
10

11  
12 Likewise, even when intervention was considered likely, the need to repeat  
13  
14 treatment that has been traumatic or to potentially need to undergo further  
15  
16 treatment that could be disfiguring or disabling in some way was stated as  
17  
18 promoting fear.  
19  
20

21  
22 *“Seeing people with half a face... if I had any more removed from my mouth I’d end*  
23  
24 *up like my friend who’s had her jaw out” (10F74I)*  
25

26  
27 The impact that a recurrence might have on the participant’s family members  
28  
29 was a common concern. This aspect of FCR was raised particularly in cases where  
30  
31 the participant acted as a carer for a family member or had children.  
32

33  
34 *“I got the people that I’m very worried about, when I started me daughter was only*  
35  
36 *18... and I look after me Mum who’s 98 in January” (5F63I)*  
37

38  
39 For some, it was the specific impact of cancer that created their fear. When a  
40  
41 participant believed that the cancer would have a significant negative effect on their  
42  
43 physical health causing certain death, this triggered FCR, regardless of whether this  
44  
45 belief was centred in a realistic assessment of the physical impact of recurrence.  
46

47  
48 *“I believe I’m either going to choke to death or starve to death, one of the two”*  
49  
50 *(2M55I)*  
51  
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3 GRATITUDE TO HEALTH CARE PROFESSIONALS AND THE IMPACT ON EXPRESSION OF  
4  
5 FEARS  
6  
7

8 Many participants described feeling uncomfortable, in some way, in raising  
9  
10 FCR with their clinicians, and, if not for the PCI, felt that this was not something that  
11  
12 they would be able to raise independently. The central reason for this appears to be  
13  
14 due to of a sense of gratitude to their clinicians and a sense of causing them offence  
15  
16 by suggesting that the treatment received may not have been fully successful.  
17  
18 Deference to their clinician's expert knowledge and understanding of their illness  
19  
20 meant that participants were unwilling to raise any concerns that could be perceived  
21  
22 as challenging this authority.  
23  
24

25  
26  
27 *"You don't like to argue with what he says do you? He's the expert." (6M70I)*  
28

29 In addition, participants were fearful of impacting negatively upon a highly  
30  
31 valued relationship.  
32

33  
34 *"I hope I haven't made [Dr] feel, erm, 'obviously she feels I haven't done a good job',*  
35  
36 *erm, cos that couldn't be further from the truth, cos I've got so much faith" (8F50)*  
37

38 There was a belief that raising any concerns that might imply that clinicians  
39  
40 had not done a good job or had missed something could create offence which was  
41  
42 something to be actively avoided.  
43  
44

45  
46 *"you want to please the people who give you this chance" (7M55I)*  
47

48 Similarly, participants did not want to be seen to be complaining by people  
49  
50 who they held in such high esteem.  
51

52  
53 *"I don't want to appear ungrateful, I don't know what's the matter with me" (9F76I)*  
54  
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3 Accordingly, participants were reluctant to raise FCR without prompting.

4  
5 *“if that hadn’t been brought up and that hadn’t have been spoken about, I’d have*  
6  
7 *come out of there in the same way, as I went in there” (5F63I)*

8  
9  
10 In addition, participants expressed that they did not expect emotional  
11  
12 *support from their consultant over and above what they already provide:*

13  
14 *2M55I: Er, the specialist cancer health, erm, has been provided by [PROF1] team and*  
15  
16 *he’s got a damn sight more important things on his hands such as other people to*  
17  
18 *cure who are suffering from cancer, er, than to be holding my hand all the time or,*  
19  
20 *to, keep trying to work, work me head better, and so I’ll go to me GP [Cough] sorry,*  
21  
22 *I’ll go to me GP over that.*

23  
24  
25  
26  
27  
28  
29 *Interviewer: “And, would, is it just do you think oh they’re too busy or do you not*  
30  
31 *really feel comfortable talking about that sort of thing with the clinical team?”*

32  
33 *5F63I: “I think, I think I suppose it’s a bit of both, I think they’re too busy, think*  
34  
35 *they’ve got enough to do I mean they’re got a lot of people in the same boat and*  
36  
37 *y’know they’ve got a lot of dealing with more, the actual physical things with you, so*  
38  
39 *I don’t think, I just don’t think to go in and put, I don’t see what they can do about it I*  
40  
41 *suppose, so you go in, sort the problem out, or say your fine or whatever happens to*  
42  
43 *be, get on with that and I wouldn’t dream of bothering them. But I don’t say I*  
44  
45 *wouldn’t be comfortable because as I say when I spoke to Doctor about it, this time,*  
46  
47 *honestly I walked out the other day when we were there and I got into my car and I*  
48  
49  
50  
51  
52 *felt fantastic.”*

## Discussion

### Interpretation of main findings

In our study, we observed that in almost all of the consultations, the consultant brought up the issue of FCR and led the discussion. The use of PCI, appeared to facilitate the identification and elaboration of psychosocial issues, in particular, FCR which may have gone undetected otherwise. It is possible that without the prompting that this consultant gave in the initial stages of the consultation that FCR concerns would have still been expressed by the patient later in the consultation. It is possible that the use of the PCI itself may provide the patient with a sufficient sense of 'permission' to raise this concern. A recent report in the same specialist clinical service (with different clinicians) tends to support this suggestion with a greater likelihood of clinicians responding with providing opportunity for patients to discuss their emotional cue or concern expression with increased duration of the consultation (Zhou et al., 2014). However, we should recognize that it is possible that the patients might have still broached their concern regarding recurrence without the use of PCI.

We observed that several methods were employed in the consultation to deal with FCR. For instance, the consultant validated this fear for the patient by normalising its presence. However, the use of an emotional validation of this fear was not taking place in isolation. The consultant also conducted a physical examination, which provided further highly relevant and personalised health information. The close physical intimacy and delicate examination used by the clinician (neck palpation) to detect potentially swollen lymph nodes, for example, reinforces the clinical relationship with the patient and consultant's credibility to

1  
2  
3 give statements on health status and recommendations. It was also apparent that  
4  
5 there was due caution in what the physical examination indicated, wherever  
6  
7 necessary.  
8  
9

10 Other methods for elaborating on the patient's health status was to  
11  
12 contextualise the results of the examination, wound healing, and general progress  
13  
14 for the patient. This included highlighting aspects of the participant's disease in  
15  
16 relation to time since diagnosis and how it compares to other types of cancer. These  
17  
18 'factual' elements of cancer were raised to 'reassure' the patient by concentrating  
19  
20 on the positive indications. It appeared that the consultant was actively attempting  
21  
22 to assist with the creation of a mental model of the cancer the participant had and  
23  
24 link this model to the emotional experience of the cancer and recurrence threat  
25  
26 (Leventhal et al., 2004). The consultation also involved discussion of how to assist  
27  
28 with the coping of these fears and included negotiating when the next follow-up  
29  
30 appointment would take place and offering emotional counselling referral. In many  
31  
32 cases, bringing up the possibility of referral to emotional support was welcome and  
33  
34 taken up on two of the cases.  
35  
36  
37  
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39

40 Following the consultations, we interviewed the participants with regard to  
41  
42 their experience and management of these fears and the extent to which the  
43  
44 consultations assisted them. We found that participants mentioned several triggers  
45  
46 of this fear, including encountering representations of cancer in media that they felt  
47  
48 they had little control over as well as experiencing physical symptoms. Particularly,  
49  
50 the role of physical symptoms as a strong determinant of fears about cancer  
51  
52 returning was one of the major findings of a recent systematic review (Simard et al.,  
53  
54 2013) and an early theoretical formulation of FCR (Lee-Jones et al., 1997). Previous  
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1  
2  
3 experience of cancer, especially, witnessing the death of a parent was also related to  
4  
5 the experience of these fears. A recent paper has formally constructed the  
6  
7 mechanism of how an individual may have increased health anxiety due to exposure  
8  
9 of parental illness (Alberts and Hadjistavropoulos, 2014). Participants also perceived  
10  
11 the possibility of recurrence particularly threatening, implying a death sentence the  
12  
13 second time round. Participants mentioned using distraction as a way of coping with  
14  
15 fears of cancer coming back.  
16  
17

18  
19 The personality feature of having a positive attitude was also perceived as  
20  
21 helping with how one deals with this fear. It is known from an extensive literature  
22  
23 review that optimism is associated with more problem-focused coping (Nes and  
24  
25 Segerstrom, 2006). The added value of being of an optimistic personality is that the  
26  
27 individual can adjust their coping approach according to the limits of being able to  
28  
29 chance the 'stressor', in this case the possibility of a cancer recurrence. These views  
30  
31 expressed about remaining positive are a reflection of the Mental Adjustment to  
32  
33 Cancer scale. A recent report of a Korean short version of this measure confirmed  
34  
35 that fatalism and fighting spirit could be encapsulated into a factor more widely  
36  
37 accepted as 'positive attitudes' (Kang et al., 2008). The corollary construct of having  
38  
39 a negative attitude was to be avoided, as relayed by participants. This 'negative  
40  
41 affectivity' is an over-riding personality dimension that is likely to be implicated in  
42  
43 the development of FCR, although it has yet to be studied longitudinally to enable  
44  
45 formal testing.  
46  
47

48  
49 Implications for research and practice  
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51

52  
53 Although we observed that the participants were willing to talk about their  
54  
55 fears during follow-up once it was raised, there was also concern about what these  
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1  
2  
3 expressions of one's concerns would imply for their relationship with their care  
4  
5 provider. Participants often expressed gratitude for the care the consultant has  
6  
7 provided and expressed concern that the discussion of recurrence fears may indicate  
8  
9 to the consultant that the participant questioned their authority and expertise. In  
10  
11 addition, dealing with psychosocial issues was not perceived to be in the domain of  
12  
13 what a consultant needed to manage. A survey of oncology staff (n = 141) in  
14  
15 Australia has shown that they are aware that more than 50% of their patients suffer  
16  
17 FCR (Thewes et al., 2014) . Only one in five (21%) reported that they referred on  
18  
19 their patients with high FCR, illustrating that there are barriers to gaining  
20  
21 professional support for these patients. The positive finding from the survey was  
22  
23 that the vast majority (99%) were interested to receive training in assisting patients  
24  
25 with high FCR levels.  
26  
27  
28  
29

30  
31 It may be worthwhile for health care professionals to be aware of the feelings  
32  
33 of gratitude for the treatment they have provided and how from their patients'  
34  
35 perspective these feelings can impede the discussions of these fears. Clinicians may,  
36  
37 for example, need to adopt sensitive language to facilitate this communication. We  
38  
39 need to recognize that reassurance can provide a short-term relief for the anxiety  
40  
41 which can further reinforce reassurance-seeking behaviour (Salkovskis, 1996). It is  
42  
43 important that reassurance is provided within the context of restructuring or  
44  
45 reformulating the content of the worry, in other words, the risk of recurrence.  
46  
47  
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50  
51 Importantly, within the context of psychosocial care of cancer patients,  
52  
53 detecting these fears (either through PCI or by simply asking about them) needs to  
54  
55 be coupled with the provision of further support and therapeutic assistance by  
56  
57 psycho-oncology services, if required. Patients with moderate to extensive FCR levels  
58  
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1  
2  
3 need to receive patient-centred support or intervention that is commensurate with  
4  
5 their clinical presentation (Cruickshank et al., In press). A previous report has  
6  
7 highlighted this difficulty for cancer treatment services: There is reticence to invite  
8  
9 discussion about psychological problems associated with the diagnosis, treatment  
10  
11 and follow-up care because of lack of training, poor methods of screening and  
12  
13 minimal provision of referral centres for specialist services (Absolom et al., 2011). It  
14  
15 is important to be aware that patients with high levels of distress may in fact receive  
16  
17 identical support from services such as cancer nurse specialists. However, what  
18  
19 appears central is the patient *impression* of the support received. This has been  
20  
21 reported to be deficient in the most distressed patient receiving comparable services  
22  
23 (Clark et al., 2009).  
24  
25  
26  
27

28  
29 In terms of research, our study was limited to one clinical setting and to one  
30  
31 clinician with a special interest in FCR which is a limitation of our study. Future work  
32  
33 needs to confirm our findings in other settings and with multiple clinicians. In  
34  
35 addition, future work needs to examine whether these fears can be raised during  
36  
37 consultation without the use of a tool such as PCI.  
38  
39

#### 40 Strengths and Limitations

41  
42  
43 This is the first study to our knowledge that has drawn together audio-  
44  
45 recordings of out-patient follow-up consultations and in-depth interviews with the  
46  
47 patients involved. The ability to match the experience of the clinic visit and the  
48  
49 patient's detailed expression of their concerns felt within the session and how they  
50  
51 might have been revealed was highly instructive and we believe has identified some  
52  
53 important interactional and clinical management processes. Our study, as  
54  
55 acknowledged above as a limitation, included a single cancer centre and only one  
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3 consultant who has a special interest in patient-centred care by developing the PCI  
4  
5 which may have increased the likelihood that patients' concerns were discussed. In  
6  
7 that regard, we should be cautious in generalising from these findings. We do  
8  
9 recognise that this means that these research questions need to be examined in  
10  
11 multiple oncology settings with different health care professionals. It is also possible  
12  
13 that the recording of the session might have impacted the session but we are  
14  
15 reassured that several participants mentioned that they did not feel the consultation  
16  
17 was any different (though not systematically assessed). We also were missing one  
18  
19 consultation and one interview recording. We have not kept track of how many  
20  
21 participants were approached and therefore do not know how representative these  
22  
23 participants are of the patients seen at this clinic. Nonetheless, these findings are  
24  
25 novel and give some important insight for guiding and planning further research and  
26  
27 clinical interventions.  
28  
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32

### 33 Conclusion

34  
35  
36 In conclusion, our findings have implications both for patients and health  
37  
38 care professionals who are in contact with them. General models of good practice  
39  
40 and also systems of evaluation of the ways in which enhanced communication can  
41  
42 facilitate health care are well-acknowledged (Back et al., 2005, Street et al., 2009,  
43  
44 Fellowes et al., 2004). Our findings indicate that patients may feel reluctant to raise  
45  
46 their fears about cancer returning with their clinician for fear of appearing  
47  
48 'ungrateful' or of damaging a relationship that is held in high esteem. In addition,  
49  
50 patients prioritise the physical aspects of their care and have reduced expectations  
51  
52 to received emotional support from their clinicians. They are quite aware of the  
53  
54 pressures on the clinics and staff time. This raises the possibility that FCR is under-  
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1  
2  
3 reported within this patient group. In the case of this study, patients were  
4  
5 encouraged to express fears, however, this may reflect the fact that the consultant  
6  
7 in question had a special interest in FCR **which is acknowledged above**. Whether this  
8  
9 communication practice is achievable in other oncology settings needs to be  
10  
11 addressed. The consultant highlighted FCR as an issue in the consultation if the  
12  
13 patient had indicated they wanted to discuss this concern **using the PCI**. It is likely  
14  
15 that explicitly raising the issue of FCR with the patient may remove the identified  
16  
17 barrier to disclosing FCR in the clinic setting **providing** the possibility of organising  
18  
19 support for those with high levels of FCR.  
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## References

- 1  
2  
3  
4  
5 ABSOLOM, K., HOLCH, P., PINI, S., HILL, K., LIU, A., SHARPE, M., RICHARDSON, A.,  
6 VELIKOVA, G. & COLLABORATIVE, N. C. S. A. P. C. R. 2011. The detection and  
7 management of emotional distress in cancer patients: the views of health-  
8 care professionals. *Psycho-Oncology*, 20, 601-8.  
9  
10 ALBERTS, N. M. & HADJISTAVROPOULOS, H. D. 2014. Parental illness, attachment  
11 dimensions, and health beliefs: testing the cognitive-behavioural and  
12 interpersonal models of health anxiety. *Anxiety, Stress, and Coping*, 27, 216-  
13 28.  
14  
15 ARORA, N. K. 2003. Interacting with cancer patients: the significance of physicians'  
16 communication behavior. *Soc Sci Med*, 57, 791-806.  
17  
18 BACK, A. L., ARNOLD, R. M., BAILE, W. F., TULSKY, J. A. & FRYER-EDWARDS, K. 2005.  
19 Approaching difficult communication tasks in oncology. *CA Cancer J Clin*, 55,  
20 164-77.  
21  
22 BRAUN, V. & CLARKE, V. 2006. Using thematic analysis in psychology. *Qualitative*  
23 *Research in Psychology*, 3, 77-101.  
24  
25 BUTOW, P., KELLY, S., THEWES, B., HRUBY, G., SHARPE, L. & BEITH, J. 2014.  
26 Attentional bias and metacognitions in cancer survivors with high fear of  
27 cancer recurrence. *Psycho-Oncology*.  
28  
29 CLARK, L., HOLCOMBE, C., HILL, J., DOWNEY, H., FISHER, J., KRESPI, M. R. & SALMON,  
30 P. 2009. The perception of support received from breast care nurses by  
31 depressed patients following a diagnosis of breast cancer. *Annals of the Royal*  
32 *College of Surgeons of England*, 91, 43-5.  
33  
34 CRUICKSHANK, S., STEEL, E., FENLON, D., ARMES, J., SCANLON K, BANKS, E. &  
35 HUMPHRIS, G. In press. A feasibility study of the Mini-AFTER telephone  
36 intervention for the management of fear of recurrence in breast cancer  
37 survivors: a mixed-methods study proto.  
38  
39 CUSTERS, J. A., GIELISSEN, M. F., DE WILT, J. H., HONKOOP, A., SMILDE, T. J., VAN  
40 SPRONSEN, D. J., VAN DER VELD, W., VAN DER GRAAF, W. T. & PRINS, J. B.  
41 2017. Towards an evidence-based model of fear of cancer recurrence for  
42 breast cancer survivors. *J Cancer Surviv*, 11, 41-47.  
43  
44 DALY, J., KELLEHEAR, A. & GLIKSMAN, M. 1997. *The public health researcher: A*  
45 *methodological approach*, Melbourne, Australia, Oxford University Press.  
46  
47 DENFORD, S., HARCOURT, D., RUBIN, L. & PUSIC, A. 2011. Understanding normality:  
48 a qualitative analysis of breast cancer patients concepts of normality after  
49 mastectomy and reconstructive surgery. . *Psycho-Oncology*, 20, 553-558.  
50  
51 FELLOWES, D., WILKINSON, S. & MOORE, P. 2004. Communication skills training for  
52 health care professionals working with cancer patients, their families and/or  
53 carers. *Cochrane Database Syst Rev*, Cd003751.  
54  
55 GHAZALI, N., CADWALLADER, E., LOWE, D., HUMPHRIS, G., OZAKINCI, G. & ROGERS,  
56 S. N. 2013. Fear of recurrence among head and neck cancer survivors:  
57 longitudinal trends. *Psycho-Oncology*, 22, 807-13.  
58  
59 GROB, S. E., NITZSCHE, A., GLOEDE, T. D., ANSMANN, L., STREET, R., PFAFF, H.,  
60 NEUMANN, M., WIRTZ, M., BAUMANN, W., SCHMITZ, S. & ERNSTMANN, N.  
2014. The initial clinical interview-can it reduce cancer patients' fear? .  
*Supportive Care in Cancer*.

- GROSS, S. E., NITZSCHE, A., GLOEDE, T. D., ANSMANN, L., STREET, R., PFAFF, H., NEUMANN, M., WIRTZ, M., BAUMANN, W., SCHMITZ, S. & ERNSTMANN, N. 2015. The initial clinical interview--can it reduce cancer patients' fear? *Support Care Cancer*, 23, 977-84.
- HODGES, L. J. & HUMPHRIS, G. M. 2009. Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psychooncology*, 18, 841-8.
- HUMPHRIS, G. M. & OZAKINCI, G. 2006. Psychological responses and support needs of patients following head and neck cancer. *International Journal of Surgery*, 4, 37-44.
- KANG, J. I., CHUNG, H. C., KIM, S. J., CHOI, H. J., AHN, J. B., JEUNG, H. C. & NAMKOONG, K. 2008. Standardization of the Korean version of Mini-Mental Adjustment to Cancer (K-Mini-MAC) scale: factor structure, reliability and validity. *Psycho-Oncology*, 17, 592-7.
- LEBEL, S., OZAKINCI, G., HUMPHRIS, G., MUTSAERS, B., THEWES, B., PRINS, J., DINKEL, A. & BUTOW, P. 2016. From normal response to clinical problem: definition and clinical features of fear of cancer recurrence. *Support Care Cancer*, 24, 3265-8.
- LEE-JONES, C., HUMPHRIS, G., DIXON, R. & HATCHER, M. B. 1997. Fear of cancer recurrence--a literature review and proposed cognitive formulation to explain exacerbation of recurrent fears. *Psycho-Oncology*, 6, 95-105.
- LEVENTHAL, H., HALM, E., HOROWITZ, C., LEVENTHAL, E. A. & OZAKINCI, G. 2004. Living with chronic illness: A contextualized, self-regulation approach. In: SUTTON, S., BAUM, A. & JOHNSTON, M. (eds.) *The Sage Handbook of Health Psychology*. Sage.
- LLEWELLYN, C. D., WEINMAN, J., MCGURK, M. & HUMPHRIS, G. 2008. Can we predict which head and neck cancer survivors develop fears of recurrence? *J Psychosom Res*, 65, 525-32.
- MCGINTY, H. L., SMALL, B. J., LARONGA, C. & JACOBSEN, P. B. 2016. Predictors and patterns of fear of cancer recurrence in breast cancer survivors. *Health Psychol*, 35, 1-9.
- MUTSAERS, B., JONES, G., RUTKOWSKI, N., TOMEI, C., SEGUIN LECLAIR, C., PETRICONE-WESTWOOD, D., SIMARD, S. & LEBEL, S. 2016. When fear of cancer recurrence becomes a clinical issue: a qualitative analysis of features associated with clinical fear of cancer recurrence. *Support Care Cancer*, 24, 4207-18.
- NES, L. S. & SEGERSTROM, S. G. 2006. Dispositional optimism and coping: a meta-analytic review. *Personality and Social Psychology Review*, 10, 235-51.
- NILSSON, M. I., OLSSON, M., WENNMANN-LARSEN, A., PETERSSON, L. M. & ALEXANDERSON, K. 2013. Women's reflections and actions regarding working after breast cancer surgery - a focus group study. *Psycho-Oncology*, 22, 1639-1644.
- NORTHOUSE, L. L., MOOD, D., TEMPLIN, T., MELLON, S. & GEORGE, T. 2000. Couples' patterns of adjustment to colon cancer. *Social Science & Medicine*, 50, 271-84.
- RICE, P. & EZZY, D. 1999. *Qualitative research methods: A health focus.*, Melbourne, Australia, Oxford University Press.

- 1  
2  
3 ROGERS, S. N., EL-SHEIKHA, J. & LOWE, D. 2009. The development of a Patients  
4 Concerns Inventory (PCI) to help reveal patients concerns in the head and  
5 neck clinic. *Oral Oncology*, 45, 555-61.
- 6  
7 ROGERS, S. N., SCOTT, B., LOWE, D., OZAKINCI, G. & HUMPHRIS, G. 2010. Fear of  
8 recurrence following head and neck cancer in the outpatient clinic. *European*  
9 *Archives of Otorhinolaryngology*, 12.
- 10  
11 SALKOVSKIS, P. M. 1996. The cognitive approach to anxiety: Threat beliefs, safety-  
12 seeking behavior, and the special case of health anxiety and obsessions. *In:*  
13 SALKOVSKIS, P. M. (ed.) *Frontiers of Cognitive Therapy*. The Guilford Press.
- 14  
15 SHIM, E. J., SHIN, Y. W., OH, D. Y. & HAHM, B. J. 2010. Increased fear of progression  
16 in cancer patients with recurrence. *Gen Hosp Psychiatry*, 32, 169-75.
- 17  
18 SIMARD, S., THEWES, B., HUMPHRIS, G., DIXON, M., HAYDEN, C., MIRESKANDARI, S.  
19 & OZAKINCI, G. 2013. Fear of cancer recurrence in adult cancer survivors: a  
20 systematic review of quantitative studies. *Journal of Cancer Survivorship*, 7,  
21 300-22.
- 22  
23 STEIN, K. D., SYRJALA, K. L. & ANDRYKOWSKI, M. A. 2008. Physical and psychological  
24 long-term and late effects of cancer. *Cancer*, 112, 2577-2592.
- 25  
26 STREET, R. L., JR., MAKOUL, G., ARORA, N. K. & EPSTEIN, R. M. 2009. How does  
27 communication heal? Pathways linking clinician-patient communication to  
28 health outcomes. *Patient Educ Couns*, 74, 295-301.
- 29  
30 SWASH, B., HULBERT-WILLIAMS, N. & BRAMWELL, R. 2014. Unmet psychosocial  
31 needs in haematological cancer: a systematic review. *Supportive Care in*  
32 *Cancer*, 22, 1131-41.
- 33  
34 TASKILA, T. & LINDBOHM, M. 2007. Factors affecting cancer survivors' employment  
35 and work ability. *Acta Oncologica*, 46, 446-51.
- 36  
37 THEWES, B., BREBACH, R., DZIDOWSKA, M., RHODES, P., SHARPE, L. & BUTOW, P.  
38 2014. Current approaches to managing fear of cancer recurrence; a  
39 descriptive survey of psychosocial and clinical health professionals. *Psycho-*  
40 *Oncology*, 23, 390-6.
- 41  
42 THEWES, B., BUTOW, P., BELL, M. L., BEITH, J., STUART-HARRIS, R., GROSSI, M.,  
43 CAPP, A. & DALLEY, D. 2012. Fear of cancer recurrence in young women with  
44 a history of early-stage breast cancer: a cross-sectional study of prevalence  
45 and association with health behaviours. *Support Care Cancer*, 20, 2651-9.
- 46  
47 TRUSSON, D., PILNICK, A. & ROY, S. 2016. A new normal?: Women's experiences of  
48 biographical disruption and liminality following treatment for early stage  
49 breast cancer. *Soc Sci Med*, 151, 121-9.
- 50  
51 ZEBRACK, B. 2000. Cancer survivor identity and quality of life. *Cancer Practice*, 8,  
52 238-42.
- 53  
54 ZHOU, Y., HUMPHRIS, G., GHAZALI, N., FRIDERICHS, S., GROSSET, D. & ROGERS, S. N.  
55 2014. How head and neck consultants manage patients' emotional distress  
56 during cancer follow-up consultations: a multilevel study. *European Archives*  
57 *of Otorhinolaryngology*.
- 58  
59  
60