

Fear of cancer recurrence in oral and oropharyngeal cancer patients:

An investigation of the clinical encounter

Running title: fear of cancer recurrence

Dr Gozde Ozakinci

Dr Brooke Swash

Prof Gerry Humphris

Prof Simon Rogers

Prof Nick Hulbert-Williams

Dr Gozde Ozakinci, CPsychol (**corresponding author**), Senior Lecturer in Health

Psychology:

University of St Andrews, School of Medicine, St Andrews, KY16 9TF

[Go10@st-andrews.ac.uk](mailto:Go10@st-andrews.ac.uk) t: 01334 463521, f: 01334 467470

Dr Brooke Swash, Lecturer in psychology

University of Chester, Chritchley Building (CCR112), Parkgate Road, Chester, CH1

4BJ

[b.swash@chester.ac.uk](mailto:b.swash@chester.ac.uk) t: 01244 511938 f: 01244 511323

Prof Gerry Humphris, Professor of Clinical and Health Psychology,

University of St Andrews, University of St Andrews, School of Medicine, St

Andrews, KY16 9TF

[Gmh4@st-andrews.ac.uk](mailto:Gmh4@st-andrews.ac.uk) t: 01334 463565, f: 01334 467470

Professor Simon N Rogers, FDS RCS FRCS MD,  
Evidence-Based Practice Research Centre (EPRC), Faculty of Health and Social  
Care, Edge Hill University, St Helens Road, Ormskirk, L39 4QP and Consultant  
Regional Maxillofacial Unit, University Hospital Aintree, Liverpool, L9 1AE, UK  
[Snrogers.aintree@gmail.com](mailto:Snrogers.aintree@gmail.com)

t: 01515295287 f: 01515295288

Prof Nick Hulbert-Williams, Coaching Psychologist & Director, Chester Research  
Unit for the Psychology of Health

Department of Psychology

University of Chester

Parkgate Road

Chester

CH1 4BJ

[n.hulbertwilliams@chester.ac.uk](mailto:n.hulbertwilliams@chester.ac.uk), t: 01244 511950 f: 01244 511323

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## Abstract

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

Keywords: fear of cancer recurrence; consultations; head and neck cancer; communication; emotional regulation

## 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

reassuring as the health professional expects (Thewes et al., 2012). Hence, the patient's FCR may increase (Lee-Jones et al., 1997). Follow-up appointments often involve a physical exam or some form of screening (e.g., mammography, palpation for neck nodes) which are met with trepidation over what the tests may reveal, and the anticipation of relief when the results do not indicate recurrence (McGinty et al., 2016). As Arora (Arora, 2003) shows in a review of the literature, the health care professionals' communication behaviour (e.g., offer of choice of treatment) with survivors is an important influence on outcomes such as patient satisfaction, adherence, anxiety, and psychological distress. Hence, clinical services are obligated to ensure good communication within the clinic setting when interacting with patients so that clinicians have the opportunity to identify and manage these fears. Another recent systematic review highlighted FCR as a key unmet need for haematological cancer patients (Swash et al., 2014), thus highlighting the need to investigate beyond the common cancers and explore FCR levels and predictors in other patient groups.

In a recent study by Custers et al., (Custers et al., 2017), mediational analyses showed that internal cues such as feeling sick and bodily sensations as well as external cues such as cancer-related media news and contact with health professionals increased FCR which in turn resulted in limited planning for future and body checking. Qualitative investigation of these fears show that intrusive thoughts, distress, and impact on functioning are common features of FCR as well as features such as 'death-related thoughts', and 'belief that the cancer will return' (Mutsaers et al., 2016). To our knowledge, no qualitative study examined how the expression of FCR took place in an oncology setting and how this was addressed.

Communication between patients and health professionals in offering improved cancer care is crucial. In the domain of fear of progression which is a concept often used interchangeably with FCR, there is some evidence showing that the way in which the medical encounter takes place and information offered can have an impact on these fears (Gross et al., 2015). In Gross et al's study (Gross et al., 2015), interruptions during the initial medical encounter caused a lower decrease in fear of progression from the initial encounter to the 3-day follow-up. In addition, those patients who found the information provided comprehensible at the initial encounter, had subsequently reduced fear of progression.

The aim of this study was to investigate how head and neck cancer survivors express FCR in follow-up consultations, how a health care professional addresses recurrence fears, and examining how the survivors experience of this interaction in a follow-up interview. Specifically, we aimed to answer the following questions:

1. Is the FCR issue expressed in the consultation? And if so, who elicits the presentation of this fear?
2. How does the consultant manage the patient's FCR, should it arise in the consultation?
3. What factors might be responsible for some patients to focus intensely on FCR? How do they self-manage this fear and any triggers for it?
4. How do survivors respond to the discussion around FCR? Specifically, did the discussion ease their concerns and abate their anxiety?

## 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

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

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

### *Data Analysis*

Questions 1 and 2 were addressed by an analysis of consultation recordings, whereas questions 3 and 4 were mainly addressed through analyses of follow-up interview data. Audio-recordings of both the consultations and interviews were transcribed verbatim. All data were analysed using a thematic analysis approach (Braun and Clarke, 2006) with a further content analysis employed within the transcripts of the consultations. Thematic analysis is a qualitative approach that has often been utilised within psycho-oncology research (e.g., (Nilsson et al., 2013, Denford et al., 2011)) and involves the identification of themes that emerge as important for the description of the phenomenon in question (Daly et al., 1997). In order for themes to be identified, a process of reading, note taking, then re-reading



the data in order to begin to recognise patterns within the data must take place (Rice and Ezzy, 1999). Emergent themes, then, become the basis of the analysis.

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

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

## Results

### *Study Population*

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

### *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, proceeded 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.

*'..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.

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

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

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

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

The consultant often offered this service facility and on two occasions, this was accepted.

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

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

#### *Analysis of Patient Interviews*

The analysis of the participants' interviews revealed a range of themes relating to patients' FCR and key barriers for these fears to be expressed and managed.

#### TRIGGERS OF FCR

Participants identified a series of triggers for their fears, some of which were directly related to sensations within their bodies while others were related to external events.

When patients noticed potential symptoms of a recurrence, this immediately created concerns. If an area of the body that had been previously affected by cancer, generally the throat or the mouth, became sore or changes of any kind were observed, then this was experienced as a strong trigger for FCR.

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

While symptoms that were directly related to the previous cancer were related to FCR, so were somatic concerns more generally. Some participants associated any changes or pains within their bodies as being potential indicators of a recurrence, regardless of how common or unrelated the perceived symptom might be.

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

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

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

Follow-up appointments were either seen in a strongly positive manner or were deemed something to be feared. In either case, knowing that they were going to see their clinician imminently meant that participants were unable to avoid their fears and the possibility that they would soon be given the bad news that their cancer had returned.

*"I am terrified for coming seeing you, I'm actually sitting here terrified to walk through that door" (3M62I)*

#### COPING WITH FCR

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

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

Some participants felt that their ability to cope, or not, with their diagnosis was in part due to their personality. Some participants believed that their underlying personality meant that they were more able to keep positive despite their fears, while others identified their FCR as being inevitable given their natural propensity to worry.

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

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

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

#### RELEVANCE OF PERSONAL HISTORY

A person's background and the prior knowledge and experiences that they brought to their cancer experience was felt to strongly impact upon how cancer was perceived by the individual. Having a family history of cancer, particularly, where a family member had passed away as a result of the disease, was believed to compound any fears about the cancer returning.

*“watching, erm, me Dad getting eaten away by cancer. And seeing the way he went and having the fear of if... am I gonna go down that road?” (4F60I)*

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

*“the tracheotomy is the worst thing you could have” (10F74I)*

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

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

#### THE CAUSES OF PARTICIPANTS’ FEARS

Some specific triggers and correlates to the presence of FCR have been highlighted. Having to cope again with the shock of a diagnosis and the difficulties of treatment should the cancer return was identified as a concern. Participants felt unsure as to whether they were physically and emotionally strong enough to repeat their previous experience of cancer.

*“I feel as though... I don’t know what I’d do if it reappeared” (8F50I)*

Many expressed the worry that if the cancer returned, it would be untreatable and that the diagnosis would be terminal.

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

Likewise, even when intervention was considered likely, the need to repeat treatment that has been traumatic or to potentially need to undergo further treatment that could be disfiguring or disabling in some way was stated as promoting fear.

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

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

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

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

*“I believe I’m either going to choke to death or starve to death, one of the two” (2M55I)*



## GRATITUDE TO HEALTH CARE PROFESSIONALS AND THE IMPACT ON EXPRESSION OF FEARS

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

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

In addition, participants were fearful of impacting negatively upon a highly valued relationship.

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

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

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

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

*"I don't want to appear ungrateful, I don't know what's the matter with me" (9F76I)*

Accordingly, participants were reluctant to raise FCR without prompting.

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

In addition, participants expressed that they did not expect emotional support from their consultant over and above what they already provide:

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

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

*5F63I: “I think, I think I suppose it’s a bit of both, I think they’re too busy, think they’ve got enough to do I mean they’re got a lot of people in the same boat and y’know they’ve got a lot of dealing with more, the actual physical things with you, so 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 suppose, so you go in, sort the problem out, or say your fine or whatever happens to be, get on with that and I wouldn’t dream of bothering them. But I don’t say I wouldn’t be comfortable because as I say when I spoke to Doctor about it, this time, honestly I walked out the other day when we were there and I got into my car and I 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

give statements on health status and recommendations. It was also apparent that there was due caution in what the physical examination indicated, wherever necessary.

Other methods for elaborating on the patient's health status was to contextualise the results of the examination, wound healing, and general progress for the patient. This included highlighting aspects of the participant's disease in relation to time since diagnosis and how it compares to other types of cancer. These 'factual' elements of cancer were raised to 'reassure' the patient by concentrating on the positive indications. It appeared that the consultant was actively attempting to assist with the creation of a mental model of the cancer the participant had and link this model to the emotional experience of the cancer and recurrence threat (Leventhal et al., 2004). The consultation also involved discussion of how to assist with the coping of these fears and included negotiating when the next follow-up appointment would take place and offering emotional counselling referral. In many cases, bringing up the possibility of referral to emotional support was welcome and taken up on two of the cases.

Following the consultations, we interviewed the participants with regard to their experience and management of these fears and the extent to which the consultations assisted them. We found that participants mentioned several triggers of this fear, including encountering representations of cancer in media that they felt they had little control over as well as experiencing physical symptoms. Particularly, the role of physical symptoms as a strong determinant of fears about cancer returning was one of the major findings of a recent systematic review (Simard et al., 2013) and an early theoretical formulation of FCR (Lee-Jones et al., 1997). Previous

experience of cancer, especially, witnessing the death of a parent was also related to the experience of these fears. A recent paper has formally constructed the mechanism of how an individual may have increased health anxiety due to exposure of parental illness (Alberts and Hadjistavropoulos, 2014). Participants also perceived the possibility of recurrence particularly threatening, implying a death sentence the second time round. Participants mentioned using distraction as a way of coping with fears of cancer coming back.

The personality feature of having a positive attitude was also perceived as helping with how one deals with this fear. It is known from an extensive literature review that optimism is associated with more problem-focused coping (Nes and Segerstrom, 2006). The added value of being of an optimistic personality is that the individual can adjust their coping approach according to the limits of being able to change the 'stressor', in this case the possibility of a cancer recurrence. These views expressed about remaining positive are a reflection of the Mental Adjustment to Cancer scale. A recent report of a Korean short version of this measure confirmed that fatalism and fighting spirit could be encapsulated into a factor more widely accepted as 'positive attitudes' (Kang et al., 2008). The corollary construct of having a negative attitude was to be avoided, as relayed by participants. This 'negative affectivity' is an over-riding personality dimension that is likely to be implicated in the development of FCR, although it has yet to be studied longitudinally to enable formal testing.

#### Implications for research and practice

Although we observed that the participants were willing to talk about their fears during follow-up once it was raised, there was also concern about what these

expressions of one's concerns would imply for their relationship with their care provider. Participants often expressed gratitude for the care the consultant has provided and expressed concern that the discussion of recurrence fears may indicate to the consultant that the participant questioned their authority and expertise. In addition, dealing with psychosocial issues was not perceived to be in the domain of what a consultant needed to manage. A survey of oncology staff (n = 141) in Australia has shown that they are aware that more than 50% of their patients suffer FCR (Thewes et al., 2014) . Only one in five (21%) reported that they referred on their patients with high FCR, illustrating that there are barriers to gaining professional support for these patients. The positive finding from the survey was that the vast majority (99%) were interested to receive training in assisting patients with high FCR levels.

It may be worthwhile for health care professionals to be aware of the feelings of gratitude for the treatment they have provided and how from their patients' perspective these feelings can impede the discussions of these fears. Clinicians may, for example, need to adopt sensitive language to facilitate this communication. We need to recognize that reassurance can provide a short-term relief for the anxiety which can further reinforce reassurance-seeking behaviour (Salkovskis, 1996). It is important that reassurance is provided within the context of restructuring or reformulating the content of the worry, in other words, the risk of recurrence.

Importantly, within the context of psychosocial care of cancer patients, detecting these fears (either through PCI or by simply asking about them) needs to be coupled with the provision of further support and therapeutic assistance by psycho-oncology services, if required. Patients with moderate to extensive FCR levels

need to receive patient-centred support or intervention that is commensurate with their clinical presentation (Cruickshank et al., In press). A previous report has highlighted this difficulty for cancer treatment services: There is reticence to invite discussion about psychological problems associated with the diagnosis, treatment and follow-up care because of lack of training, poor methods of screening and minimal provision of referral centres for specialist services (Absolom et al., 2011). It is important to be aware that patients with high levels of distress may in fact receive identical support from services such as cancer nurse specialists. However, what appears central is the patient *impression* of the support received. This has been reported to be deficient in the most distressed patient receiving comparable services (Clark et al., 2009).

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

#### Strengths and Limitations

This is the first study to our knowledge that has drawn together audio-recordings of out-patient follow-up consultations and in-depth interviews with the patients involved. The ability to match the experience of the clinic visit and the patient's detailed expression of their concerns felt within the session and how they might have been revealed was highly instructive and we believe has identified some important interactional and clinical management processes. Our study, as acknowledged above as a limitation, included a single cancer centre and only one

consultant who has a special interest in patient-centred care by developing the PCI which may have increased the likelihood that patients' concerns were discussed. In that regard, we should be cautious in generalising from these findings. We do recognise that this means that these research questions need to be examined in multiple oncology settings with different health care professionals. It is also possible that the recording of the session might have impacted the session but we are reassured that several participants mentioned that they did not feel the consultation was any different (though not systematically assessed). We also were missing one consultation and one interview recording. We have not kept track of how many participants were approached and therefore do not know how representative these participants are of the patients seen at this clinic. Nonetheless, these findings are novel and give some important insight for guiding and planning further research and clinical interventions.

## Conclusion

In conclusion, our findings have implications both for patients and health care professionals who are in contact with them. General models of good practice and also systems of evaluation of the ways in which enhanced communication can facilitate health care are well-acknowledged (Back et al., 2005, Street et al., 2009, Fellowes et al., 2004). Our findings indicate that patients may feel reluctant to raise their fears about cancer returning with their clinician for fear of appearing 'ungrateful' or of damaging a relationship that is held in high esteem. In addition, patients prioritise the physical aspects of their care and have reduced expectations to received emotional support from their clinicians. They are quite aware of the pressures on the clinics and staff time. This raises the possibility that FCR is under-



reported within this patient group. In the case of this study, patients were encouraged to express fears, however, this may reflect the fact that the consultant in question had a special interest in FCR which is acknowledged above. Whether this communication practice is achievable in other oncology settings needs to be addressed. The consultant highlighted FCR as an issue in the consultation if the patient had indicated they wanted to discuss this concern using the PCI. It is likely that explicitly raising the issue of FCR with the patient may remove the identified barrier to disclosing FCR in the clinic setting providing the possibility of organising support for those with high levels of FCR.

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