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Does Emotional Talk Vary with Fears of Cancer Recurrence Trajectory? A Content Analysis of Interactions between Women with Breast Cancer and their Therapeutic Radiographers

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#### Abstract

Fears of cancer recurrence (FCR) in patients with breast cancer are hypothesised to develop over the period from diagnosis, through treatment and thereafter. A crucial point may be the contact that patients have with their therapeutic radiographer in review appointments. The study aimed to (1) describe and categorise the content of the identified emotional talk, and (2) consider the evidence for an association of content with FCR trajectory.

Methods: A concurrent mixed methods approach was applied as part of a larger investigation (FORECAST) of breast cancer patients (n = 87). Patients completed a daily diary during their radiotherapy treatment. Audio recordings were collected of review appointments. The Verona Coding Definitions of Emotional Sequences (VR-CoDES) system was used to code patient emotional cues and concerns (CCs). Purposeful sampling of the daily diary ratings identified 12 patients (30 consultations) with an increasing (n=6) or decreasing (n=6) FCR trajectory. The emotional talk of these patients at their weekly reviews was content analysed.

Results: Four themes were identified from 185 CCs: Physical Symptoms, Factors External to Hospital, Treatment, and Labelling Cancer. FCR decreasing trajectory group consultations were longer (p < 0.02), expressed twice as many CCs as the increasing trajectory group (p < 0.001), and were more likely to refer to cancer directly (p < 0.05).

Conclusions: The emotional content expressed matched features outlined in the Lee-Jones *et al* (1997) FCR model, and showed evidence of avoidance in increasing FCR trajectory patients.

#### Introduction

Persons treated for breast cancer often experience raised levels of anxiety and depression [1-3]. However a recent review has found that an increased prevalence at 5 years post diagnosis was confirmed for depression but not for anxiety [4]. The focus on depression and anxiety has tended to ignore some pressing additional psychological needs of patients with cancer. The strongest priority as rated by patients with breast cancer, recently found that 62% wished to speak with their clinician, at the out-patient clinic, about their fears of cancer recurrence (FCR) [5]. The number of articles that document fears of recurrence is increasing and there has been an extensive review to show associations with anxiety and depression [6]. It is clear that FCR is a stable construct that is aversive to the individual at high levels. To reduce extensive FCR that has developed, through specialist intervention, is complex and resource intensive [7-9]. A preventive approach is therefore indicated.

Our group has investigated the factors that may exacerbate FCR [10, 11]. As part of this work we are researching (FORECAST study) the interactions that clinicians have with their patients during the course of their treatment [12]. For oncology patients there is time taken in clinical appointments to discuss treatment options. Information delivered at this early stage is considered important to enable patients to adjust to their changed circumstances [13]. Patients who lack information report more anxiety [14]. Halkert *et al.* surveyed 123 women longitudinally at four time points during, and immediately after treatment to enquire of their information needs and anxiety levels [15]. Information was sought throughout the treatment period and anxiety was found to be maintained until the treatment finished. However, this survey relied solely on structured questionnaires and patient self-reports. Another approach that the authors prefer is to record (via audio or video) the clinical interactions between health providers and the patient. This methodology as the advantage is that the data collected are objective and not so easily subject to social-desirability responding by patients.

Some articles report systematic methods to analyse the communication features of the clinical patient interaction [16-18]. The Verona Coding Definitions of Emotional Sequences (VR-CoDES) is a coding scheme that is especially suited to explore, in exquisite detail, the hidden emotional cues that are presented by patients, including those treated for serious diseases including cancer [19-22]. The system has been validated [23] and has already been employed in over 40 studies since its development [24]. The link between patient self-report of their concerns about cancer returning and clinical contact with their health care team has yet to be studied in detail. We are aware from one model of FCR development in patients [25] that the understanding and 'representation' of a disease such as cancer is constructed by vital information sources including staff contacts. Not only is the cognitive aspect (e.g. information) of the disease important but also the emotional response that patients have to these relevant stimuli. The self-regulation model outlined by Lee-Jones et al. incorporates the parallel-processing of cognition and emotion [25]. Hence our approach has been to examine closely the interactions at a key stage of treatment, specifically the review appointments, when patients are encouraged to describe their current state of health during the radiotherapy treatment process. We are aware of no other investigation that has investigated sequential interactions in the review appointments of patients with breast cancer receiving radiotherapy.

#### **Aims**

- Present and critically analyse the content of female breast cancer patients'
  emotional talk (cues and concerns) through the course of radiotherapy, in the
  weekly review consultations with therapeutic radiotherapists.
- 2. Investigate the association of emotional talk content to patients' fears of cancer recurrence trajectories (increasing or decreasing) assessed during treatment.

#### Methods

#### **Participants**

Data were collected from an observational cohort study of adult female breast cancer patients and radiotherapists, in which their one-on-one consultations at a specialist breast cancer centre in Scotland, were audio recorded. One of two radiotherapists led review consultations held with patients receiving radiotherapy as primary or adjunctive treatment for their cancer. Patients self-rated their fears of cancer recurrence (FCR) pre-radiotherapy, and daily throughout their two to three-week treatment period (ranging 15 to 25 days). The rating consisted of a 3 item scale (FCR3) that assessed FCR. The reliability of this scale has been shown to be high (0.92) with a mixed sample of breast and colorectal cancer patients, and some evidence of validity has been indicated through confirmation of unidimensionality and relatedness with associated psychological constructs [26]. Those in rank order with the most positive or negative overall change in their FCR from baseline to the end of their therapy were selected. The principle of "maximum variation" sampling, a form of purposeful qualitative sampling, was applied to enable the greatest chance of demonstrating an effect [27]. In total, 12 patients, with a repeated set resulting in thirty consultations, were regarded as sufficient to provide a corpus of data establishing support for the hypothesised association of content to FCR change [27, 28]. The number of participants selected were identical to a similar study using maximum variation sampling in cancer patients [29]. Hence, six patients with the largest FCR increases from baseline, and six with the largest decreases, were selected. Participants were volunteers, communicated in English and had no known psychiatric conditions. The radiotherapy regime was the final primary treatment element for these patients at the centre, before a conventional out-patient follow-up protocol with the

necessary occasional check-up. Ethical approval was granted by NRES (reference number: 13/ES/0015).

Design, procedure & analyses

A concurrent mixed-methods explorative design was used [30] (p22). This approach 'mixes' both the quantitative and qualitative data corpuses as defined in a recent review [31]. Quantitative (trajectories from diary ratings) and qualitative (audio tape transcripts) methodologies were applied. A content analysis [32] using a stepwise deductive-inductive procedure [33], was conducted on patients' emotional talk. This involved both theory and data-driven coding, and therefore combines deduction and induction. The initial step involved deductively identifying topics of interest, based on theory. This step was achieved by coding the audiotapes for emotional events (cues and/or concerns; or "CCs") with the widely used VR-CoDES system, using the event logging software Observer XTv12. Two researchers coded the tapes following training from GH and an inter-rater reliability analysis was conducted to assess general agreement [34]. Any discrepancy or difficulty in assigning the cues' or concerns' utterances was discussed with the principle investigator (GH), and consensus achieved to ensure a complete identification of these crucial events. The next step involved induction, and every identified emotional "cue" and "concern" uttered by the patient, was rewritten into a shorter phrase or a few words conveying the content onto an index card. This procedure is similar to "systematic text condensation" [28], which forms condensates or artificial quotes from actual quotes. These condensed descriptors were then inductively grouped according to their main content, and finally grouped into over-arching final themes. This grouping was conducted blindly, so that the specific patient and their FCR trajectory (increasing or decreasing) was unknown. This procedure adopted to enhance validity and trustworthiness [35] was undertaken separately by two of the authors (LB and

GH), who then deliberated and decided on the final themes summarising the content of patients' emotional talk. Once the overarching themes were agreed upon, an inter-rater reliability analysis determined the level of agreement in allocating the descriptors throughout these themes, as followed by Moretti *et al.*[36] Any remaining disparities in descriptor allocation were discussed and mutually reallocated, resulting in the final themes and membership of each CC. We present quotes in tabular form (Table 4) and within the results text.

Statistical analyses (alpha set to 0.05, 2 sided) included z, t and likelihood ratio tests, where appropriate, to supplement the findings of the content analysis, particularly comparing CC frequency, duration of consultation and theme allocation across relevant groupings.

#### **Results**

#### **Demographics**

Participants were all married and lived with at least one other person, apart from one (8%) patient. She was single and lived alone, and was situated in the increasing FCR group. Only two (17%) were educated to degree level, both in the increasing group. Seven (58%) were employed and five were retired or unemployed (42%). Six (50%) had chemotherapy prior to radiotherapy, four of these being in the decreasing FCR group (see Table 1).

#### Consultations

There were 30 consultations in total, and the average number per patient was identical for both FCR trajectory groups (M = 2.5, SD = 0.52). The maximum number of consultations per patient was three. One radiotherapist conducted 17 (57%) consultations and the other, 13 (43%). There were equal number of consultations in the increasing and decreasing FCR

groups, that is 15 each. The increasing FCR group had an average consultation time of 7 mins 58 secs (SD = 10 mins 7 secs) and the decreasing group an average of 12 mins 26 secs (SD = 12 mins 36 secs); the grand average for all patients was 10 mins 12 secs (SD = 12 mins 21 secs). The decreasing FCR group's consultations were therefore 4 mins 28 secs longer on average, and each patient in this group had an average 11 mins 10 secs of extra total consultation time in total. There was a significant difference in consultation length between these FCR trajectory groups (t(29)=2.23, p=0.02).

VR-CoDES: Emotional Talk

Inter-rater reliability analysis of codes' frequency and sequence, based on two randomly selected consultations, suggested substantial agreement between the two researchers implementing VR-CoDES (Kappa = 0.6 (95% CIs = 0.42, 0.77); Spearman's Rho = 0.77, p = < 0.001).

In total, 185 CCs were expressed: 60 (32.4%) in the increasing FCR group, and 125 (67.6%) in the decreasing group, the latter expressing over double the number of CCs than the former. Patient 'seven' in the decreasing group had 59 CCs across two consultations, which was appreciably higher than others. A single sample z-test of proportion found the decreasing group to have a significantly larger proportion of CCs than the increasing group (z = 4.79, p = < 0.001).

Concerns were expressed by seven out of 12 (58.3%) patients. Four patients in the FCR decreasing group issued eight concerns in total, whereas three patients in the FCR increasing group presented three concerns, i.e. one each. The total CCs per consultation (one to three) across all patients are presented in Table 2.

The first consultation tended to have the most CCs, which decrease for all patients by the third (final) consultation compared to the first two. When examined by group, number of CCs

in the final consultation is similar in both groups, with only 6 more CCs (17.6%) in the increasing group. CCs in consultations one and two are much higher in the decreasing trajectory group however.

#### **Themes**

After conducting individual content analyses on the data, both researchers agreed that four overall themes emerged, namely: 1) Physical Symptoms, 2) Factors External to Hospital, 3) Treatment, and 4) Labelling Cancer. Initially one researcher divided theme two into "Family and Spouse" and "Occupation", but this was collapsed into the current theme after authors' deliberation. A preliminary inter-rater reliability analysis of the researchers' independent allocation of descriptors to these four agreed themes, resulted in very good agreement across all themes (k = 0.78 (95% CI = 0.71, 0.85), p < 0.001). Thirteen sub-themes were identified and this detailed categorisation within themes showed good consistency between researchers (k = 0.56 to 0.9). Table 3 presents the CC allocation to broad themes across patients. Table 4 presents example CC quotes. All quotes are italicised and referenced by Patient number (P) and Session number (S). The ellipsis (, , , ) denotes omitted speech. See Supplementary Tables 1-4 for detailed description of these themes.

The review appointments, averaging just over 10 minutes, contained a mean of six CCs. There was high variability, with one patient expressing 59 total CCs and another only four. Of the four major themes of emotional talk it was found that the majority focused on physical symptoms (44%), followed by factors external to hospital (28%), labelling cancer (18%) and treatment (11%). The four major themes (and 13 sub-themes) are presented in Table 4. Theme 1 includes emotional CCs categorised as physical symptoms. As well as expressing emotions relating to radiotherapy side-effects (hot flushes, tiredness) patients also expressed concern for unrelated bodily symptoms (e.g. neck goitre, sciatica, surgical scar-

tissue). Patients did sometimes ask about inexplicable symptoms which worried them, often in their breast tissue; but usually not in direct reference to recurrence

"I still get those sharp shooting pains" (P54S2).

It is possible that patients were raising these additional issues about physical symptoms as they were not receiving information from their doctors:

"I'm still numb, and a bit stiff. I'm not quite sure if it's, you know, kind of where it's from?" (P2S3)

Theme 2 included emotional issues arising from content external to the hospital, focusing on family or work. The latter were a mixture of worry about returning to work and wanting to return to regain normality:

"It's (work) kind of a, double edged sword!" (P2S3).

Colleagues' lack of understanding was common, especially about fatigue:

"and...(colleagues) not getting the whole, the fatigue thing" (P2S3).

Concern for their spouse's physical and mental health surrounding their breast cancer was expressed frequently, with some claiming they worry more about their husband's reaction than themselves

"In fact, I'm more worried about him" (husband) P20S2).

Some of the women were aware of their husband's distress:

"He (husband) was really worried, that it (cancer) was maybe...
going somewhere else... aww what a shame "! (P20S2).

Some patients referring to close family members who have had cancer before. One patient expressed negative emotions surrounding chance media exposures: cancer charity adverts:

"they (adverts) absolutely annoy me" P6S1).

Some express annoyance at family and friends being overbearing towards them, attempting to restrict their physical activity for instance:

"while you are all (family) sitting there saying, you need to do this, don't do that, you don't need to do that, why? why? ... do I look like I've got a big C on the other side of me, and I've changed?" (P6S1).

The third theme focused on CCs that were associated with treatment. Contemplating the loss of these regular appointments with the radiotherapists evoked negative emotions in multiple patients, in the treatment theme. The thought of being without these review visits was considered as "bizarre" and "weird" (P20S2) to some. Other content included surgery (reconstruction or mastectomy), with patients expressing worry or wishing to avoid the intervention

("I don't think I'm going to go down that road (reconstruction)...

I think I've been through enough" (P45S2).

One patient was distressed her mastectomy was unnecessary, as prior surgery had not been performed successfully

"...it (mastectomy) bugs me" (P22S2).

Others expressed a distain for their medication, and some conveyed dissatisfaction with their surgery, and simply not having the same doctor for each appointment

"every 'Tom Dick and Harry' has done my operations and seen me" (P22S2).

The final theme, labelling cancer, comprised content relating to the general experience of having and being diagnosed with cancer, and its implications. The only patient who lived alone in this study did not want to:

"quietly fall apart with no one noticing" (P2S3)

in the wake of her own diagnosis. The complicated nature of treatment, and the amount of knowledge patients need to remember was emphasised by some. There were also some errors in thinking held about cancer recurrence, with one patient believing:

"no matter where it (cancer) is in your system, there's no way they can get it all" (P6S1).

Some stated they "know" their cancer will return, potentially influenced by their past and family or friends' cancer experiences:

"...she (sister) was the first one to get the cancer, well my dad died of lung cancer... and all his siblings died of cancer" (P6S2).

Others explained they hardly considered recurrence, but worry that the reality of their diagnosis will impact in the future.

Differences between FCR Groups

Likelihood ratio tests were conducted comparing the frequency of each theme in increasing and decreasing FCR groups. A significant effect was discovered for theme four. Patients with decreasing FCR trajectories were more likely to express CCs in the "Labelling Cancer" theme than patients with increasing FCR trajectories ( $X^2$  (1) = 4.04, p = 0.04).

#### Discussion

This is the first longitudinal study to investigate the content of emotional talk in clinical interaction with breast cancer patients, over the course of radiotherapy. This is the final treatment element for these patients prior to discharge from their frequent and concentrated span of hospital attendances. Important findings were revealed from addressing the first two study aims that related (1) to the content of emotional talk and (2) differences in content across patient FCR trajectories. The discussion will highlight these and focus on a theoretical model that may assist in explaining the phenomena revealed to complete the third aim.

Emotional Talk Content (Aim 1)

A structure of 'in-patient' and 'out-patient' dimensions was introduced to assist presentation. (Schematic diagram: Figure 1). Since radiographers provide radiotherapy treatment, education, planning and review, it was consistent that Physical Symptoms were the most frequent emotional topic expressed by patients (Theme 1). In addition, patients may be confused about the association of co-morbid conditions to their diagnosis and treatment of cancer. Alternatively, the trauma associated with their diagnosis of cancer and its consequences may, through the processes we understand are related to post-traumatic stress disorder [37], inflate patients' vigilance and increase their search for reassurance ("I am actually still a bit concerned" P59S1). Such interpretations are considered speculative at present as caution is required prior to link possible mental disordered processes to conversational interactions.

In Theme 2 where CCs External to Hospital were presented, it is interesting that some of the women in this sample were aware of their husband's distress and were finding this problematic. The male response to stress is to keep the issue hidden as confirmed in a longitudinal qualitative study of male carers for breast cancer patients [38, 39]. The recognition of difficulties and unmet needs in care-givers may not be as hidden to cancer patients and perhaps service providers are not fully aware of this situation [40]. Patients

clearly used their consultations with the radiotherapists to discuss much more than just their radiotherapy treatment and symptomatic relief of side effects with skin creams and pain-relieving medication. The therapeutic radiographers were acting as supportive counsellors at times. This opportunity to act as a supporter has been recognised by Merckeart *et al.* who have introduced a fairly intensive communication skills intervention to train radiotherapists [41].

Theme 3 focussed on cues and concerns about Treatment. Of interest was the recognition raised by P88S3 that there will be a change is support when the hospital treatment appointments stop. This has been recognised as a major transition from treatment to home [42]. The topic of this transition is a prominent one for many patients and has been recognised in oncology services [42, 43].

Theme 4 on Labelling Cancer included CCs with the explicit sub-theme of recurrence. This is referred to in the following trajectories section.

FCR Trajectories: (Aim 2)

The most striking difference between the trajectory groups was the number of CCs. The FCR decreasing group expressed over twice (125) the CCs than the FCR increasing group (60). Even controlling for length of consultation did not explain this difference. This tentatively indicated that more expression of negative emotions related to a lowering of FCR over the treatment period. A possible explanation may be that these patients were ventilating their emotion or unburdening themselves [44]. Equally, they may have been reporting low FCR but simply more open to expressing negative emotions.

Examined by consultation, CC numbers reduced with each consultation for all patients, suggesting negative emotions subsided as treatment progressed. The most prevalent CCs overall and for each group, in rank order, were: B, D, C, A, Concern, E then G. The category

of Cue B was the most common has been reported previously in the oncology field [45]. This reflects the prevalence of themes also, as external factors (family, work: akin to cue D) and physical symptoms (akin to cue C) were the most frequent. There is some consistency between VR-CoDES and our identified themes, but the Verona coding scheme deliberately omits specific content. A clear example was the emotional talk content about physical symptoms, the most commonly identified theme. The Labelling Cancer theme was expressed significantly more in the FCR decreasing group compared with the increasing group. There were no other differences between trajectory groups - suggesting that the women who reported that their FCR was decreasing were also able to express emotions concerning cancer recurrence, diagnosis and implications more readily than those with increasing FCR. Again, some unburdening process might mean explicitly discussing recurrence fears reduces patients' FCR. However, in some of these utterances patients claimed they had no fears at all, suggesting the reduction in FCR may have come before they expressed this issue anyway. Alternatively, overexpression of claims that no such fears existed might form part of some defence mechanism.

#### Links to Lee-Jones et al. FCR Model [25]

As raised briefly in the introduction this model outlines the major factors contributing to patients' development and personal management of FCR, many of which are evident in the present study. Examples of processes reflecting many of the main elements of the Lee-Jones et al. model were found. Patients' personal recurrence risk estimates (i.e. cognitions) were formed via past cancer experiences, knowledge of survival rates and beliefs about cancer eradication. Many patients referred to family members who had experienced or died from cancer. However, some patients expressed inaccurate cancer treatment beliefs, believing that cancer can never be cured. One increasing FCR trajectory patient expressed clear worry about an upcoming cancer scan potentially missing something - partly due to her previous

experiences, and partly due to her regret for not having had a more detailed scan.

Behavioural responses to FCR included body-checking, but there was little evidence of obsessive breast checking expressed as emotional talk. Almost all patients sought advice from the radiotherapist, and from other doctors, as an apparent behavioural response to sensation or physical side effects during the treatment process.

In terms of psychological effects, patients did misinterpret symptoms at times and expressed somatic anxiety. The radiotherapists tackled these utterances of patients, by explaining that the symptoms of radiotherapy can cause unusual breast sensations. Many of the issues that arose in the discussions with the radiographer were similar to breast cancer survivors, notably 'confusion about symptoms, and using self-prescribe remedies' and 'recurrence fears' [46]. Antecedents of FCR are categorised in the Lee-Jones et al. model in the form of internal and external triggers. The latter linked clearly to our second theme, with these triggers potentially increasing the emotional content of the patients' speech during the highly relevant interactions during the review appointments with their keyradiographer. The emotional content was observed naturalistically in these interactions. Hence, close analysis of patientclinician speech may provide a test-bed to demonstrate the veracity of the Lee-Jones et al. model by demonstrating the potential associations of this phenomenon with increasing FCR levels. This approach we believe is supportive of other conventional cross-sectional data collection studies which impose a causal mediation model. We believe that the potential for studying a more flexible methodology of multiple time points within and across interactions over time introduces novel and rich possibilities to endorse the Lee-Jones et al. model. This is supported by Leventhal's expansion of his common-sense model (CSM) to explicate the parallel-processing system of emotions and cognitions in patients in transit from active treatment to out-patient follow-up: "A mix of methods can more effectively address the components and assemble a model of the system that is both implicit and explicit in CSM"

[47]. The dynamic nature of these changes is reflected in both the procedures advocated in our study and can act as points of contact to intervene with patients [48, 49].

#### Limitations and future work

Although some quantitative analysis was conducted we are aware that due to limited sample size the power available is limited and will only reveal large effect sizes. In addition, the comparison of themes between the two FCR trajectory groups involved multiple testing and one was found to show statistical significance. We appreciate that this finding should be considered with caution. We have been deliberately selective in our choice of patients with clear trajectories (both +ve and -ve) in their concerns about cancer recurring. This will, by the nature of the selection, negate generalisation. However we were interested to demonstrate the issues that are expressed by patients during their radiotherapy treatment, especially when there appears to be contrasting psychological processing, that is reflected in opposite patterns of FCR trajectories.

We are aware that differences between the two groups' trajectories in these women maybe a result of some personality variation. It is known for example that optimism [50, 51] predicts the development of FCR and this is a testable hypothesis for future investigation. Multiple repeated testing of FCR levels provides the ability to estimate trajectories. We have modelled (estimating trajectories) with this type of psychometric diary data using the principles outlined by Nezlek [52]. The question that such repeated testing of FCR might sensitise the individual respondent is not supported in our experience from informal discussions with participants in this study. We note that other researchers have tested FCR with extensive instruments monthly [53] or shorter duration of a few days repeatedly [54]. The repeated assessment of psychological constructs presents some challenges of interpretation that are resolvable. Such challenges are outweighed by the richness of data

collected and patterns that are revealed [55]. Additional work is required using 'intentional missing-data designs' to test the sensitisation hypothesis in further studies [56].

Future work might expand the collection of audio-tapes of review appointments, coding emotional talk at each of the review meetings and analysing the change of FCR over the time of the treatment regimen. An important prediction to test might be the association of levels of spoken emotional expression about cancer and ratings of FCR and subsequent levels of FCR at follow up appointments.

#### Conclusion

This study successfully identified and examined emotional talk over multiple consultations in breast cancer patients during their final phase of treatment. Four emotional 'talk' themes were identified. Negative emotions decreased over time across all patients, but some differences were also found between FCR trajectory groups - including more emotional expression in the decreasing group. Decreasing FCR group patients also expressed more CCs particularly in the first two consultations, whilst CCs in the last were about the same for both groups. All themes appeared in both groups, although the "Labelling Cancer" theme was more likely to be expressed by the FCR decreasing group patients.

#### **Conflicts of Interest**

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All authors declare no conflicts of interest.

#### References

- [1] Reich M, Lesur A, Perdrizet-Chevallier C. Depression, quality of life and breast cancer: a review of the literature. Breast cancer research and treatment. 2008;110:9-17.
- [2] Matthews H, Grunfeld EA, Turner A. The efficacy of interventions to improve psychosocial outcomes following surgical treatment for breast cancer: a systematic review and meta-analysis. Psychooncology. 2016.
- [3] Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. Psychooncology. 2001;10:19-28.
- [4] Maass SW, Roorda C, Berendsen AJ, Verhaak PF, de Bock GH. The prevalence of long-term symptoms of depression and anxiety after breast cancer treatment: A systematic review. Maturitas. 2015;82:100-8.
- [5] Kanatas A, Lowe D, Velikova G, Roe B, Horgan K, Shaw RJ, et al. Issues patients would like to discuss at their review consultation in breast cancer clinics -- a cross-sectional survey. Tumori. 2014;100:568-79.
- [6] Simard S, Thewes B, Humphris G, Dixon M, Hayden C, Mireskandari S, et al. Fear of cancer recurrence in adult cancer survivors: a systematic review of quantitative studies. J Cancer Surviv. 2013;7:300-22.
- [7] van de Wal MA, Gielissen MF, Servaes P, Knoop H, Speckens AE, Prins JB. Study protocol of the SWORD-study: a randomised controlled trial comparing combined online and face-to-face cognitive behaviour therapy versus treatment as usual in managing fear of cancer recurrence. BMC psychology. 2015;3:12.
- [8] Smith A, Thewes B, Turner J, Gilchrist J, Fardell J, Sharpe L, et al. Pilot of a theoretically grounded psychologist-delivered intervention for fear of cancer recurrence (Conquer Fear). Psychooncology. 2015;24:967-70.
- [9] Humphris G, Ozakinci G. The AFTER intervention: A structured psychological approach to reduce fears of recurrence in patients with head and neck cancer. British Journal of Heal th Psychology. 2008;13:223-30.
- [10] Yang Y, Cameron J, Humphris G. The relationship between cancer patient's fear of recurrence and radiotherapy: a systematic review and meta-analysis. Psychooncology. 2016.
- [11] Yang Y, Yunhong W, Bedi C, Humphris G. The Relationship between Cancer Patient's Fear of Recurrence and Chemotherapy: A Systematic Review and Meta-Analysis. In Press.
- [12] Humphris G, Yuan Y, Barracliffe L, Cameron J, Bedi C. Therapeutic Radiographer responses to emotional talk in breast cancer patients undergoing radiotherapy: A longitudinal multi-level sequential study. International Conference on Communication in Healthcare. Baltimore, USA 2017.
- [13] Gross SE, Nitzsche A, Gloede TD, Ansmann L, Street R, Pfaff H, et al. The initial clinical interview-can it reduce cancer patients' fear? Support Care Cancer. 2015;23:977-84.
- [14] Jefford M, Tattersall MH. Informing and involving cancer patients in their own care. The Lancet Oncology. 2002;3:629-37.
- [15] Halkett GK, Kristjanson LJ, Lobb E, Little J, Shaw T, Taylor M, et al. Information needs and preferences of women as they proceed through radiotherapy for breast cancer. Patient Educ Couns. 2012;86:396-404.
- [16] Tay LH, Hegney D, Ang E. Factors affecting effective communication between registered nurses and adult cancer patients in an inpatient setting: a systematic review. International journal of evidence-based healthcare. 2011;9:151-64.
- [17] Roter D, Larson S. The Roter interaction analysis system (RIAS): utility and flexibility for analysis of medical interactions. Patient Educ Couns. 2002;46:243-51.
- [18] Krupat E, Frankel R, Stein T, Irish J. The Four Habits Coding Scheme: validation of an instrument to assess clinicians' communication behavior. Patient Educ Couns. 2006;62:38-45.
- [19] Zimmermann C, Del Piccolo L, Bensing J, Bergvik S, De Haes H, Eide H, et al. Coding patient emotional cues and concerns in medical consultations: the Verona coding definitions of emotional sequences (VR-CoDES). Patient Educ Couns. 2011;82:141-8.

- [20] Del Piccolo L, de Haes H, Heaven C, Jansen J, Verheul W, Bensing J, et al. Development of the Verona coding definitions of emotional sequences to code health providers' responses (VR-CoDES-P) to patient cues and concerns. Patient Educ Couns. 2011;82:149-55.
- [21] Finset A, Heyn L, Ruland C. Patterns in clinicians' responses to patient emotion in cancer care. Patient Educ Couns. 2013;93:80-5.
- [22] Del Piccolo L, Finset A, Mellblom A, Figueiredo-Braga M, Korsvold L, Zhou Y, et al. Verona Coding Definitions of Emotional Sequences (VR-CoDES): Conceptual Framework and Future Directions. Submitted.
- [23] Eide H, Eide T, Rustoen T, Finset A. Patient validation of cues and concerns identified according to Verona coding definitions of emotional sequences (VR-CoDES): a video- and interview-based approach. Patient Educ Couns. 2011;82:156-62.
- [24] Del Piccolo L. VR-CoDES Network of Sequence Analysis. <a href="http://www.each.eu/sigs/verona-coding-system/2013">http://www.each.eu/sigs/verona-coding-system/2013</a>.
- [25] Lee-Jones C, Humphris G, Dixon R, Bebbington-Hatcher M. Fear of cancer recurrence: a literature review and formulation to explain exacerbation of recurrence fears. Psycho-Oncology. 1997;6:95-105.
- [26] Humphris G, Watson E, Sharpe M, Ozakinci G. Unidimensional scales for fears of cancer recurrence and their psychometric properties: The FCR4 and FCR7. submitted.
- [27] Suri H. Purposeful Sampling in Qualitative Research Synthesis. Qualitative Research Journal. 2011;11:63-75.
- [28] Malterud K. Qualitative research: standards, challenges, and guidelines. Lancet (London, England). 2001;358:483-8.
- [29] Nund RL, Ward EC, Scarinci NA, Cartmill B, Kuipers P, Porceddu SV. Carers' experiences of dysphagia in people treated for head and neck cancer: a qualitative study. Dysphagia. 2014; 29:450-8.
- [30] Johnson R, Onwuegbuzie A. Mixed methods research: A research paradigm whose time has come. Educational Researcher, 2004;33:14-26.
- [31] Zhang W, Creswell J. The use of "mixing" procedure of mixed methods in health services research. Medical care. 2013;51:e51-7.
- [32] Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qualitative health research. 2005;15:1277-88.
- [33] Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. International Journal of Qualitative Methods. 2006;5:80-92.
- [34] Fletcher I, Mazzi M, Nuebling M. When coders are reliable: the application of three measures to assess inter-rater reliability/agreement with doctor-patient communication data coded with the VR-CoDES. Patient Educ Couns. 2011;82:341-5.
- [35] Elo S, Kääriäinen M, Kanste O, Pölkki T, Utriainen K, Kyngäs H. Qualitative Content Analysis: A Focus on Trustworthiness. SAGE Open. 2014;4:2158244014522633.
- [36] Moretti F, van Vliet L, Bensing J, Deledda G, Mazzi M, Rimondini M, et al. A standardized approach to qualitative content analysis of focus group discussions from different countries. Patient Educ Couns. 2011;82:420-8.
- [37] Cordova MJ, Riba MB, Spiegel D. Post-traumatic stress disorder and cancer. The lancet Psychiatry. 2017;4:330-8.
- [38] Lopez V, Copp G, Molassiotis A. Male caregivers of patients with breast and gynecologic cancer: experiences from caring for their spouses and partners. Cancer Nurs. 2012;35:402-10.
- [39] Adams E, Boulton M, Rose PW, Lund S, Richardson A, Wilson S, et al. A qualitative study exploring the experience of the partners of cancer survivors and their views on the role of primary care. Support Care Cancer. 2012;20:2785-94.

- [40] Sklenarova H, Krumpelmann A, Haun MW, Friederich HC, Huber J, Thomas M, et al. When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. Cancer. 2015;121:1513-9.
- [41] Merckaert I, Delevallez F, Gibon AS, Lienard A, Libert Y, Delvaux N, et al. Transfer of communication skills to the workplace: impact of a 38-hour communication skills training program designed for radiotherapy teams. J Clin Oncol. 2015;33:901-9.
- [42] Allen JD, Savadatti S, Levy AG. The transition from breast cancer 'patient' to 'survivor'. Psychooncology. 2009;18:71-8.
- [43] Page JS, Lederman L, Kelly J, Barry MM, James TA. Teams and Teamwork in Cancer Care Delivery: Shared Mental Models to Improve Planning for Discharge and Coordination of Follow-Up Care. Journal of oncology practice. 2016;12:1053-8.
- [44] Detmar SB, Aaronson NK, Wever LD, Muller M, Schornagel JH. How are you feeling? Who wants to know? Patients' and oncologists' preferences for discussing health-related quality-of-life issues. J Clin Oncol. 2000;18:3295-301.
- [45] Zhou Y, Humphris G, Ghazali N, Friderichs S, Grosset D, Rogers SN. How head and neck consultants manage patients' emotional distress during cancer follow-up consultations: a multilevel study. Eur Arch Otorhinolaryngol. 2015;272:2473-81.
- [46] Roundtree AK, Giordano SH, Price A, Suarez-Almazor ME. Problems in transition and quality of care: perspectives of breast cancer survivors. Support Care Cancer. 2011;19:1921-9.
- [47] Leventhal H, Leventhal EA, Breland JY. Cognitive Science Speaks to the "Common-Sense" of Chronic Illness Management. Annals of Behavioral Medicine. 2011;41:152-63.
- [48] Leventhal H, Phillips LA, Burns E. The Common-Sense Model of Self-Regulation (CSM): a dynamic framework for understanding illness self-management. Journal of behavioral medicine. 2016;39:935-46.
- [49] Parker PA, Banerjee SC, Matasar MJ, Bylund CL, Franco K, Li Y, et al. Protocol for a cluster randomised trial of a communication skills intervention for physicians to facilitate survivorship transition in patients with lymphoma. BMJ open. 2016;6.
- [50] Llewellyn CD, Weinman J, McGurk M, Humphris G. Can we predict which head and neck cancer survivors develop fears of recurrence? J Psychosom Res. 2008; 65:525-32.
- [51] Crist JV, Grunfeld EA. Factors reported to influence fear of recurrence in cancer patients: a systematic review. Psychooncology. 2013;22:978-86.
- [52] Nezlek J. Multilevel modeling analyses of diary-style data. In: Mehl M, Conner T, editors. Handbook of research methods for studying daily life. 1st ed. New York: Guilford; 2012. p. 357-83.
- [53] Dunn LB, Langford DJ, Paul SM, Berman MB, Shumay DM, Kober K, et al. Trajectories of fear of recurrence in women with breast cancer. Support Care Cancer. 2015;23:2033-43.
- [54] McGinty H, Small B, Laronga C, Jacobsen P. Predictors and patterns of fear of cancer recurrence in breast cancer survivors. Health Psychology. 2016;35:1-9.
- [55] Nezlek J. Diary Methods for Social and Personality Psychology. London: SAGE Publications Ltd; 2012.
- [56] Little T. Longitudinal Structural Equation Modelling. New York: The Guilford Press; 2013.

**Figure 1.** Schematic of Lee-Jones *et al.* (1997) FCR model with exploded 'emotional 'talk' themes showing both In-patient and Out-patient dimensions of emotional talk. More frequent expression found in patients with decreasing FCR trajectory (dotted circle).

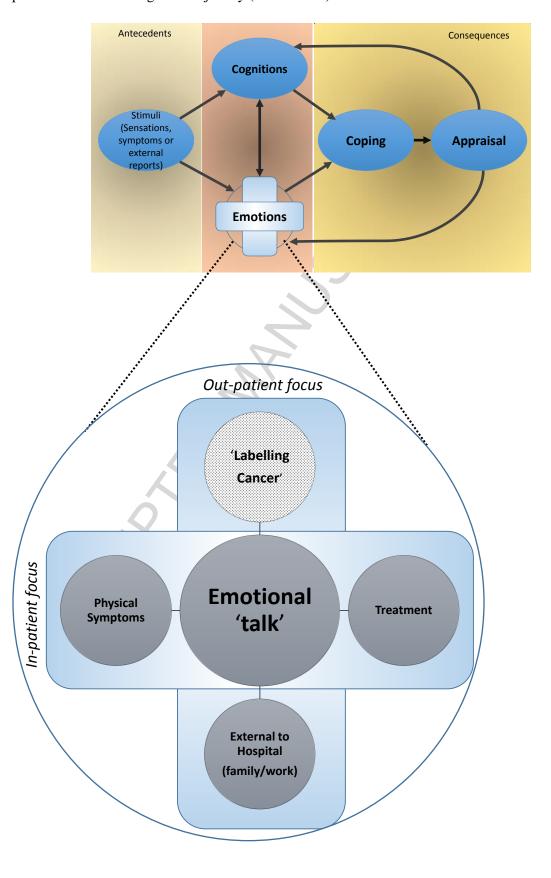


 Table 1. Patient demographics

Patier	nt	Number of	Age		Lives			
Numbe	er <sup>a</sup>	Consultations	Group	Marital Status	Alone	Education	Occupation	Chemotherapy
2	+		40 - 45		Yes	University		Yes
		3		Single		Degree	Full-time job	
22 +	+		50 - 55		No	School until		Yes
		2		Married		18 years	Part-time job	
36	+		60 - 65		No	University		
		3		Married		Degree	Full-time job	No
54	+		60 - 65		No	School until		
		3		Married		16 years	Retired	No
72	+		65 - 70		No	School until		
		2		Married		16 years	Retired	No
88	+		60 - 65		No	School until		
		2		Married		16 years	Retired	No
6	-		65 - 70		No	School until		
		2		Married		16 years	Housewife	Yes
11	-		50 - 55	•	No	School until		
		3		Married		18 years	Full-time job	Yes
20	-		55 - 60		No	School until		No
		3		Married		16 years	Part-time job	
35	-		60 - 65	<del>/                                    </del>	No	School until		No
		3		Married		16 years	Retired	
45	-		40 - 45		No	School until		
		2	W/	Married		16 years	Part-time job	Yes
59	-		55 - 60		No	School until		
		2		Married		16 years	Part-time job	Yes

Note a: -, +: Decreasing and Increasing FCR trajectories respectively

**Table 2.** CCs frequency for all patients across consultations, grouped by increasing (+ve) and decreasing (-ve) FCR trajectories, with Totals

Patient	2	22	36	54	72	88
Number:						
FCR	نعينيت والمساء		*****	*****	*****	
Trajectory:	4000					
Cue A <sup>a</sup>	1	2	0	0	1	0
Cue B	8	8	4	3	0	3
Cue C	3	2	0	3	3	0
Cue D	2	3	0	2	5	2
Cue E	2	0	0	0	0	0
Cue G	0	0	0	0	0	0
Concern	1	1	0	0	1	0
Total (+ve)	17	16	4	8	10	5
Patient	6	11	20	35	45	59
Number:			_			
FCR	***	Description of the last of the		*********	****	*********
Trajectory:		•	,			
Cue A	6	3	8	0	2	0
Cue B	28	3	16	2	2	0
Cue C	5	5	2	3	3	3
Cue D	16	1	4	1	1	1
Cue E	0	0	1	0	0	0
Cue G	0	1	0	0	0	0
	1 4	^	1	2	0	1
Concern	4	0	1	8	<u> </u>	5

#### Note *a*:

**Definitions of CCs.**  $\underline{\mathbf{A}}$  - Words or phrases in which the patient uses vague or unspecified words to describe his/her emotions.  $\underline{\mathbf{B}}$  - Verbal hints to hidden concerns (emphasizing, unusual words, unusual description of symptoms, profanities, exclamations, metaphors, ambiguous words, double negations, expressions of uncertainties and hope).  $\underline{\mathbf{C}}$  - Words or phrases which emphasise (verbally or non-verbally) physiological or cognitive correlates (regarding sleep, appetite, physical energy, excitement or motor slowing down, sexual desire, concentration) of unpleasant emotional states.  $\underline{\mathbf{D}}$  - Neutral expressions that mention issues of potential emotional importance which stand out from the narrative background and refer to stressful life events and conditions.  $\underline{\mathbf{E}}$  - A patient elicited repetition of a previous neutral expression.  $\underline{\mathbf{G}}$  - A clear and unambiguous expression of an unpleasant emotion which is in the past (more than one month ago) or is referred to an unclear period of live.  $\underline{\mathbf{Concern}}$  - A clear and unambiguous expression of an unpleasant current or recent emotion where the emotion is explicitly verbalized, with a stated issue of importance for the patient or without. Included are patient expressions confirming health provider's explicit assumption or question about an unpleasant current or recent emotion.[19]

**Table 3.** Instances of themes per patient, across all consultations

Patient		1. Physical	2. Factors External	3. Treatment	4. Labelling	Total	
Number	ı	Symptoms	to Hospital		Cancer		
2	+	6	8	1	2	17	
22	+	5	4	3	4	16	
36	+	3	0	1	0	4	
54	+	7	0	1	0	8	
72	+	7	3	0	0	10	
88	+	2	2	1	0	5	
Total (+)		30	17	7	6	60	
6	-	12	26	5	16	59	
11	-	8	0	2	3	13	
20	-	18	6	3	5	32	
35	-	6	1	1	0	8	
45	-	4	1	1	2	8	
59	-	3	0	1	1	5	
Total (-)		51	34	13	27	125	
Grand		81	51	20	33	185	
Total							

Note a: -, +: Decreasing and Increasing FCR trajectories

**Table 4.** Full (not condensed) example CC quotations for each sub-theme; a selection of 13 (7%)

Theme	Sub-theme	Full CC Quotation	Trajectory
1. Physical	1.1 Hot Flushes	"No, no, because I've got absolutely horrific sweats	-
Symptoms		and flushes" (P20S1)	
	1.2 Food & Nausea	"I just canny (can't) stand feeling sick" (P72S1)	+
	1.3 Sleep & Tiredness	"I couldn't even open my mouth to form words, I just	-
		felt so tired" (P20S3)	
	1.4 Pain	"Just taking sort of painkillers to try and sort of, take	-
		the edge off it" (P11S3)	
	1.5 Skin & Chest	"I may never get any feeling back on the skin it is	+
		what it is isn't it" (P2S3)	
2. Factors	2.1 Occupation	"I needed work to help me forget what was happening	+
External to		to me I think, and just to be a normal person" (P22S1)	
Hospital	2.2 Family & Spouse	"It's been terrible, he's (husband) been four times in,	+
		with pneumonia, and a suspected meningitis, and	
		heart problems" (P72S1)	
	2.3 Charities	"Do they know what they're bloody talking about?"	-
		(cancer charity adverts) (P6S1)	
3. Treatment	3.1 Doctors	"I'm not even going to chase him, because I'm fed up	-
		withGPs" (P11S1)	
	3.2 Medicine & Surgery	"I had three lumpectomies, before I had mastectomy,	+
		whereas if they'd just have done the 'loody (bloody)	
		thing properly" (P22S2)	
	3.3 Appointments	"I've had this life-line here (hospital appointments),	+
		and now that's allbut not coming back every single	
		day to see everybody and" (P88S3)	
4. Labelling	4.1 Recurrence &	"I know it's (cancer) gonna come back, I know within	-
Cancer	Diagnosis	myself its gonna come back" (P6S1)	
	4.2 Implications &	"I want to get back to normal" (P11S3)	-
	Consequences	-	

from all 185. FCR trajectory shown for the patient each quote originates from.

Note a: -, + = Decreasing and Increasing FCR trajectories respectively).

#### Highlights

- Breast cancer patients' emotional talk was investigated at radiography reviews
- Emotional talk about cancer featured in patients' with decreasing fears of recurrence
- Support for Lee-Jones *et al* model of recurrence fears from patients' speech content

