

Experiences of fear of cancer recurrence under standard-of-care and patient-initiated follow-up: a qualitative study of head and neck cancer patients on the PETNECK2 trial

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Background

- ⇒ Globally, head and neck cancer (HNC) is the sixth most common cancer¹. Following treatment, current UK and international guidelines recommend a 5-year follow-up period with HNC patients². There is insufficient evidence that this is the most effective and efficient follow-up to detect recurrence and patients call for a more patient-focused, individualised approach^{3,4}.
- ⇒ The PETNECK2 trial explores an alternative follow-up approach and examines the effectiveness of PET-CT imagining performed at 1-year post-treatment to determine patients at low-risk of recurrence. Patients also receive an education session from a healthcare professional resource and the PETNECK2 app or booklet that provides support to self-check, monitor symptoms and book an urgent appointment if concerned. This replaces scheduled follow-up appointments – patient-initiated follow-up (PIFU)³.
- ⇒ The PETNECK2 trial assesses a variety of outcomes, including patient survival time and cost-effectiveness, as well as patient fear of cancer recurrence (FCR). FCR is defined as ‘fear, worry, or concern relating to the possibility that cancer will come back or progress’⁵. To date, there are limited studies reporting on the link between FCR and PIFU.
- ⇒ Here we report findings from the qualitative study and explore the experience of follow-up and of FCR for patients on the control and intervention arms of the PETNECK2 trial.
- ⇒ The Common-Sense Model⁶ provides a theoretical model to understand the processes that contribute to persistent FCR.

Results

FCR Triggers

- Experience of symptoms:**
- ⇒ Experiencing physical symptoms, such as dry throat, ulcers, and aches and pains, triggered participants FCR as they associated these with possible symptoms of HNC.
 - ⇒ Participants were reminded of the consequences of cancer recurrence, such as further treatment, disability or even death, resulting in FCR.

- Others with cancer diagnoses:**
- ⇒ Learning of others with cancer acted as a reminder of participants’ own experience, triggering FCR.

- Follow-up appointments:**
- ⇒ At baseline and on the control arm, participants reported that follow-up appointments acted as a significant FCR trigger.
 - ⇒ Appointments could potentially result in the detection of recurrence, eliciting a strong emotional response including fear and anxiety.

Participant A (control):
“When you’re poorly or something like that or you’re getting a pain or a sore throat, “Could this be coming back, or not?”

Participant B (control):
“But every time you go for this, you get all worked up as well. It’s like, “God, what if they find something?””

Discussion

- ⇒ Findings of the current study were consistent with the broader literature on FCR^{8,10,11,12,13,14}. The PETNECK2 intervention increased confidence to self-check, ensured access to urgent care and the extra PET-CT scan provided lasting reassurance.

- Limitations:**
- ⇒ The current study provides insight into a 12-month period and does not explore the longer-term impact of the PETNECK2 intervention.
 - ⇒ PIFU participants were not attending follow-ups, however, were still contacted by the study team. It is unclear how this may have impacted their experience.
 - ⇒ Participant attrition was an issue faced. There was also a higher rate of attrition for PIFU participants, raising questions around whether aspects of the PETNECK2 intervention impacted engagement with the study.

- ⇒ The current study provides insight into the features of the PETNECK2 intervention that appear to promote positive coping and willingness to self-manage health. These may be important findings to further explore the suitability of PIFU for future patients, should the PETNECK2 trial identify that PIFU is effective and efficient.

Methods

- Participants:**
- ⇒ 24 participants were recruited from the PETNECK2 trial using purposive sampling to select participants that scored ≥22 on the FCRI-SF at baseline (1-year post-treatment)^{7,8}.
 - ⇒ 13 participants were on the control arm and 11 on PIFU.
 - ⇒ 17 participants completed follow-up interviews that were conducted at least 12-months post-randomisation onto the trial: 11 on the control arm and 6 on PIFU.
- Procedure:**
- ⇒ Interviews were conducted and recorded using Microsoft Teams. Interviews followed a predetermined interview schedule that was the same for all participants on baseline (1-year post-treatment) and differed depending on trial arm at follow-up (12-months post-randomisation).

- Analytical process:**
- ⇒ Reflexive thematic analysis⁹ was used to analyse the data. Coding was completed inductively and codes were grouped to begin theme development. Themes were organised deductively and mapped onto the CSM.
 - ⇒ We as researchers identified a lack of personal lived experience of HNC and survivorship and invited members of the PETNECK2 Patient Advisory Group (PAG) to contribute to the coding process. Three PAG members attended a training session and completed coding of a subset of transcripts at baseline and follow-up, and reviewed coding frameworks.

- ⇒ Baseline data was analysed as one data set. At follow-up, data was analysed by trial arm.
- ⇒ Figure 1 illustrates how data points were used.

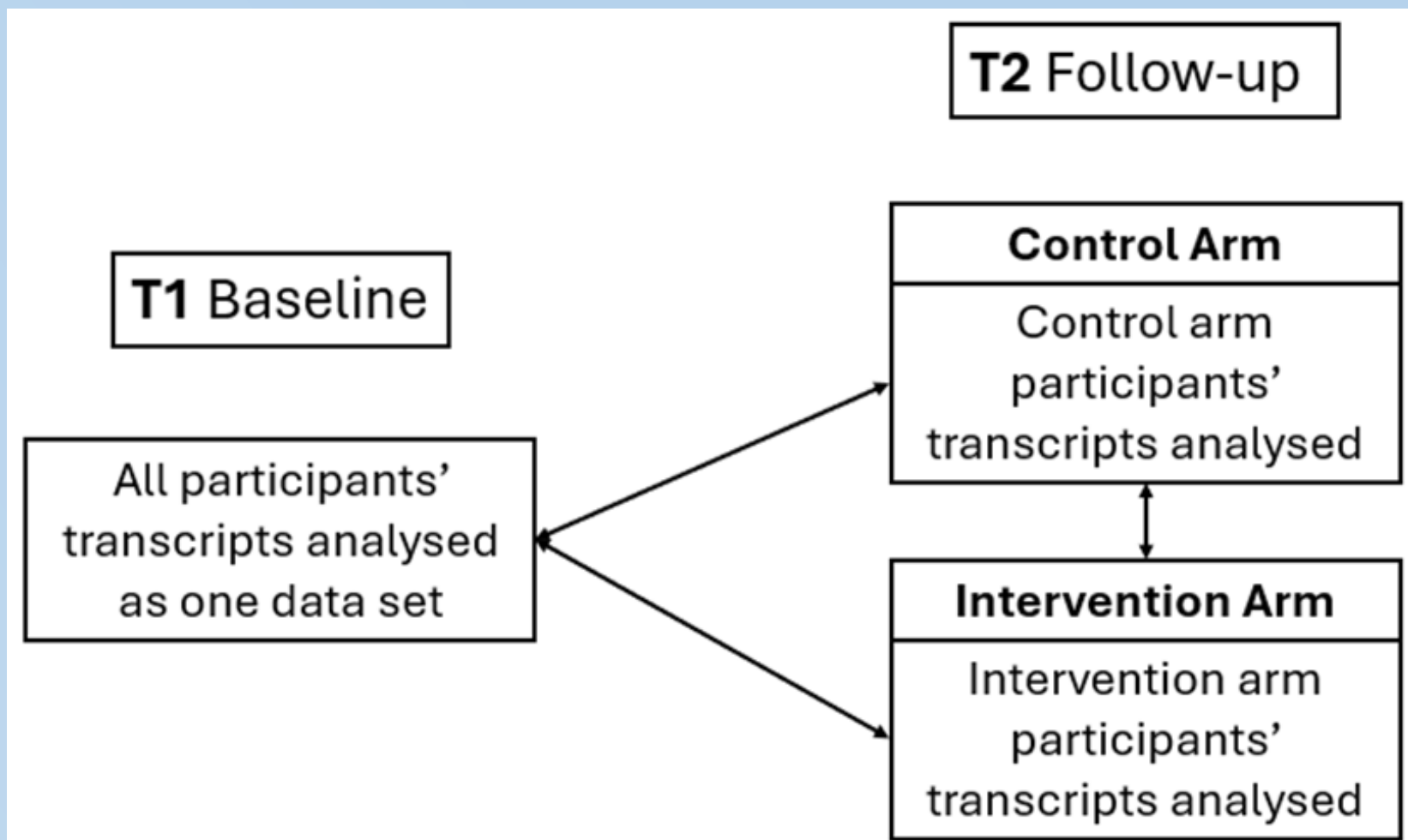


Figure 1. How data points were used in analyses

Coping Procedures

- Self-checking for symptoms:**
- ⇒ At baseline and on the control arm, participants reported increased self-checking that reinforced their FCR. Often, self-checking was driven by anxiety, felt habitual and acknowledging facial disfigurement or changes to the body all acted as reminders of the consequences of cancer.
 - ⇒ However, for PIFU participants the education session and PETNECK2 app/booklet meant self-checking had become a behaviour that allowed them to take control of their health, self-manage their wellbeing and increase their confidence.

- Avoidance:**
- ⇒ Participants stayed busy, distracted, or sometimes actively dismissed distressing thoughts.

- Social support:**
- ⇒ Support from loved ones and others with experience of cancer was valued by participants.

- Impact of PETNECK2 intervention on coping procedures:**
- ⇒ Access to healthcare - PIFU participants could access an urgent appointment and this was an acceptable replacement for scheduled follow-ups.
 - ⇒ However, some participants expressed they would value a check-in text/call from their health team.
 - ⇒ PET scan giving lasting reassurance - PIFU participants viewed the extra PET scan as a key benefit of PETNECK2 intervention. The extra scan provided significant and lasting reassurance as to the status of their health and the likelihood of cancer recurrence.

Participant C (PIFU): “This also gives you a sort of a manual as to what you're looking for. So I think it's very useful. It's useful self-help tool for anybody who's had cancer to certainly be able to, you know, examine themselves on a regular basis and make sure that they're still well.”

- Medication to manage anxiety:**
- ⇒ Some participants used medication to manage anxiety related to FCR.

- Counselling:**
- ⇒ Some participants engaged with counselling or intended to seek it out in the future. Participants found this support beneficial and reassuring that they could access it when needed.

- Importance of milestones after the end of treatment:**
- ⇒ Participants’ perception of risk of recurrence changed as they got further away from treatment.
 - ⇒ Participants reported that reaching certain milestones in their recovery, such as reaching two years cancer free, were important in reducing their FCR.

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